

**Using Illness Perceptions and Coping to Understand  
Distress and Quality of Life in  
Carers of Stroke Survivors**

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## **Overview**

The role of illness perceptions and coping in distress and quality of life in carers of stroke survivors is investigated. The first part is a review of the literature concerning the impact of stroke on carers and the research investigating determinants of poor outcomes in these individuals. Theoretical frameworks are examined with emphasis on the potential contribution of Leventhal's self-regulation model, which provides a useful framework for investigating illness perceptions and coping in stroke carer outcomes.

The empirical paper investigated the role of illness perceptions and coping in distress and quality of life in carers of stroke survivors. Seventy-two carers completed postal questionnaires. Findings indicated an important role of illness perceptions and coping in carer outcomes. Illness perceptions accounted for variance in carer distress, psychological quality of life and social relationships, over and above carer, stroke survivor and illness characteristics. Emotional representations and belief in a psychosocial cause both independently predicted greater distress. Perceptions of greater treatment control independently predicted better psychological well-being and better social relationships. Coping added significant variance in psychological and social quality of life with less use of passive coping independently predicting better psychological well-being and better social relationships. Interpretation of the findings, implications and suggestions for further research are discussed.

The critical appraisal examines further the strengths and weaknesses of the study.

Theoretical and clinical implications and suggestions for further research are elaborated.

# CONTENTS

	Page
<b>Acknowledgements</b>	<b>1</b>
<b>PART 1: LITERATURE REVIEW</b>	<b>2</b>
<b>Abstract</b>	<b>3</b>
<b>1. Introduction</b>	<b>4</b>
<b>2. Aetiology and Epidemiology of Stroke</b>	<b>5</b>
<b>3. The Importance of Carers</b>	<b>6</b>
<b>4. The Impact of Stroke on Carers</b>	<b>10</b>
<b>5. Factors Associated with Poor Outcomes in Stroke Carers</b>	<b>14</b>
5.1 Demographic Factors	14
5.2 Time Since Stroke & Number of Strokes	17
5.3 Time Spent Caring	17
5.4 Stroke Severity, Physical Disability and Functional Abilities of the Stroke Survivor	18
5.5 The Presence of Aphasia in the Stroke Survivor	20
5.6 Cognitive Impairment in the Stroke Survivor	22
5.7 Behavioural Problems in the Stroke Survivor	22
5.8 Emotional Status of the Stroke Survivor	23
5.9 Emotional Status of the Carer	23
5.10 Carer's Physical Health	24
5.11 Perception of Recovery	24
5.12 Social Networks and Support	25
5.13 Carer Appraisal of Caregiving Stress & Coping	26
<b>6. Theoretical Frameworks to Understand Carer Outcomes</b>	<b>29</b>
6.1 Pearlin's Stress Process Model	29
6.2 The Cognitive Appraisal Model of Stress & Coping	32
6.3 Family Systems Illness Model	34
<b>7. Illness Perceptions</b>	<b>36</b>
7.1 Leventhal's Self-Regulation Model	36
7.2 Illness Perceptions in Patients and Outcomes	38
7.3 Illness Perceptions in Carers/Family Members	41
<b>8. Summary</b>	<b>46</b>
<b>References</b>	<b>49</b>



	<b>Page</b>
<b>PART 2: EMPIRICAL PAPER</b>	<b>60</b>
<b>Abstract</b>	<b>61</b>
<b>Introduction</b>	<b>62</b>
<b>Method</b>	<b>72</b>
Participants	72
Ethics	73
Procedure	73
Design	75
Measures	75
<i>Demographics and Characteristics of the Carer,             Stroke Survivor and Stroke/Illness</i>	75
<i>Other Stroke Survivor Characteristics:</i>	76
<i>Barthel Index</i>	76
<i>Nottingham Extended Activities of Daily Living Index</i>	77
<i>The Speech Questionnaire</i>	77
<i>The Rayners Hedge Scales of Functional Independence IV</i>	78
<i>Other measures:</i>	79
<i>The Revised Illness Perceptions Questionnaire (IPQ-R) (modified)</i>	79
<i>Brief COPE</i>	81
<i>The General Health Questionnaire 12 item version</i>	81
<i>WHOQOL-BREF</i>	82
<b>Results</b>	<b>83</b>
Descriptives	83
<i>Characteristics of the Carers &amp; Stroke Survivors</i>	83
<i>Characteristics of the Illness/Stroke</i>	84
<i>Data Transformations</i>	85
<i>Measures of Stroke Survivor Characteristics</i>	86
<i>Illness Perceptions of Stroke Carers</i>	86
<i>Coping Behaviours of Carers</i>	88
<i>Distress and Quality of Life of Carers of Stroke Survivors</i>	89
Univariate Correlations	89
<i>Correlations with Distress</i>	91
<i>Correlations with Quality of Life</i>	94
Regression Analyses	95
<i>Predicting Distress</i>	96
<i>Predicting Physical Quality of Life</i>	97
<i>Predicting Psychological Quality of Life</i>	97
<i>Predicting Social Quality of Life</i>	98
<i>Predicting Environmental Quality of Life</i>	99

	<b>Page</b>
<b>Discussion</b>	<b>100</b>
Predicting Distress	101
Predicting Quality of Life	104
Limitations	110
Implications	112
Future Research	114
Conclusion	115
<b>References</b>	<b>116</b>
 <b>PART 3: CRITICAL APPRAISAL</b>	 <b>126</b>
<b>Introduction</b>	<b>127</b>
<b>Strengths and Limitations</b>	<b>129</b>
Groundwork	129
Sample	131
Measures	132
Design	138
Analysis	139
<b>Implications</b>	<b>140</b>
<b>Future Research</b>	<b>143</b>
<b>Conclusion</b>	<b>144</b>
<b>References</b>	<b>145</b>
 <b>APPENDICES</b>	 <b>148</b>
I    Response Rates	148
II   Power Calculation	149
III  Ethics Approval Letter and R&D PCT Approval Letter	150
IV   Initial Invitation Letter to Stroke Survivors	154
V    Carer Information Sheet	157
VI   Carer Consent Form	159
VII  Letter to Stroke Survivors' GP	160
VIII Reminder Letter to Stroke Survivors	161
IX   Letter to Consenting Carers	164
X    Reminder Letter to Carers	165
XI   Questionnaire Pack	166
XII  Additional illness Characteristics	182

## **CONTENTS: TABLES**

	<b>Page</b>
Table 1: Key characteristics of the carers and stroke survivors	83
Table 2: Means, standard deviations and Cronbach alphas for measures concerning patient characteristics	86
Table 3: Means, standard deviations and Cronbach alpha scores of the IPQ-R (modified) in carers of stroke survivors	87
Table 4: Means, standard deviations and Cronbach alphas for distress and quality of life in carers of stroke survivors	89
Table 5: Correlations between the illness perceptions and coping variables in the final analysis: Pearsons r	90
Table 6: Correlations between carer, patient and illness characteristics with distress and quality of life	92
Table 7: Correlations between illness perceptions/coping with distress and quality of life	93
Table 8: Summary of stepwise multiple regression analysis testing the predictors of distress.	96
Table 9: Summary of stepwise multiple regression analysis testing the predictors of physical quality of life	97
Table 10: Summary of stepwise multiple regression analysis testing the predictors of psychological quality of life	98
Table 11: Summary of stepwise multiple regression analysis testing the predictors of social quality of life	99
Table 12: Summary of stepwise multiple regression analysis testing the predictors of environmental quality of life	99

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## **Part 1: Literature Review**

### **Understanding the Determinants of Distress and Quality of Life in Carers of Stroke Survivors: A Review of the Literature**

## **Abstract**

Stroke is considered to be one of the most predominant causes of disability. Those individuals who return home following a stroke often receive support and care from family members. It has not been until relatively recently that carers needs have been recognised despite a burgeoning of research that has identified that caring for a family member is a stressful experience. Carers of stroke survivors have been found to experience high levels of depression, distress, strain and anxiety. This review considers the literature that has examined the impact of stroke on carers. The research that has investigated possible determinants of poor outcomes in carers of stroke survivors is discussed. Central to this review is the exploration of the theoretical frameworks that might explain poor outcomes in carers, with particular emphasis on the potential contribution of Leventhal's self-regulation model. The self-regulation model is presented as a useful framework to investigate illness perceptions, coping, distress and quality of life in carers of stroke survivors.

# **Understanding the Determinants of Distress and Quality of Life in Carers of Stroke Survivors: A Review of the Literature**

## **1. Introduction**

The impact of caring for a family member has been well recognised as a stressful experience (Thompson, Blundek & Sobolew-Shubin, 1990; Zarit & Edwards, 1999). In the 2000 General Household Survey, carers were asked for the first time about the effect that caring has had on them both physically and emotionally and 39% of carers reported that their physical and mental health had been affected by their caring role (Office of National Statistics, 2002). Carers looking after someone in the same household reported more health problems as a consequence of their role than those caring for someone who lived elsewhere. The caring role may become difficult to continue effectively if the strain that the caregiver experiences is difficult for them to manage. This could have negative consequences for the person that they are caring for and increased demands on services. Equally important are the needs of family carers themselves. They represent a high risk group and should be considered in their own right beyond their role as a carer.

Recent national clinical guidelines for stroke (Intercollegiate Stroke Working Party, 2004) recommend that carers' needs should be considered from the outset in terms of information provision, planning and decision making and professional support. These guidelines acknowledge that it is not until recently that the degree of stress and the characteristics influencing the nature and extent of stress in carers has been investigated.

This review begins by presenting a brief outline of the aetiology and epidemiology of stroke. This will be followed by an overview of the importance of carers with reference to Government reforms and the contribution that carers make towards stroke survivors' well-being. The impact and consequences of stroke on carers will be summarised and this will be followed by a discussion of research findings concerning the determinants of poor outcomes in carers. Finally, the possible processes or theoretical frameworks that might be applied to understanding poor outcomes in carers will be considered. In particular, Leventhal's self-regulation model and the role of illness perceptions in understanding distress and quality of life in carers of stroke survivors will be discussed.

## **2. Aetiology and Epidemiology of Stroke**

Stroke has been defined as rapidly developing signs of focal or global disturbance of cerebral functions, with symptoms lasting more than 24 hours or until sudden death, with no cause other than of vascular origin (World Health Organization, 1978). A stroke occurs when blood flow to the brain is disrupted, leading to a lack of oxygenated blood to the brain. This causes damage or death of brain cells. Disruption of blood flow may occur through obstruction of the blood vessels to the brain or through haemorrhage. The effects of stroke can be variable and partly depend on the area of the brain affected. Common symptoms and long term consequences of stroke can include weakness, paralysis or numbness on one side of the body; speech and language deficits; visual or perceptual difficulties; cognitive problems; behavioural difficulties; emotional changes and other physical problems such as bowel and bladder incontinence.



There are many risk factors for stroke including hypertension, smoking, excessive high consumption of alcohol, diabetes, high cholesterol, obesity, heart disease, atrial fibrillation and abnormalities in blood clotting.

It is estimated that, each year, 110,000 people in England and Wales have a first stroke with around 10,000 of these under 55 years old (Department of Health, 2001). Mant, Wade & Winner (2004) estimate that, each year, between 174 and 216 people per 100,000 of the population in England and Wales have a first stroke. Fatality following a first stroke has been found to be between 19% and 34% in the first 28 days after stroke and this figure rises to between 33% and 40% in the first 3 months after stroke (Mant et al., 2004). Stroke represents the third most common cause of death in the UK (Department of Health, 2001). While many survive and make a good recovery, many others are left with severe physical and/or cognitive disability. Indeed, stroke is thought to be the largest single cause of severe disability in the UK (Department of Health, 2001). It is estimated that the risk of a recurrent stroke within 5 years of a first stroke is between 30% and 43% (Mant et al., 2004).

### **3. The Importance of Carers**

In the 2000 General Household Survey, it was estimated that there were 6.8 million adult carers in Britain (Office of National Statistics, 2002). This represents approximately one in six people aged 16 or over caring for a sick, disabled or elderly relative and one in five households containing a carer. Of these 6.8 million carers, 28% spent at least 20 hours per week in their caring tasks and about half of these were looking after someone that required constant attention.

It was not until 1995 that ‘carers’ were specifically mentioned in law. This came with the Carers (Recognition and Services) Act 1995. This gave carers the right to request an assessment of their ability to provide and continue to provide care. While this assessment had to consider decisions about the services provided to the care recipient, it did not follow that the local authority had a duty to provide services for carers.

In 1999, the Government published the National Strategy for Carers (Department of Health, 1999a), recognising that carers needs were “currently only being met patchily.” This document consists of three strategic elements which are information, support and care. The first includes improved information for carers (e.g. about what to expect from services and good health information) and information about carers. Support includes involving carers in planning and providing services and consultation with local organisations. The last strategic element, care, focuses on addressing carers’ own needs. Indeed, the Carers (Recognition and Services) Act 1995 had not focused on services specifically for carers in their own right.

The Carers and Disabled Children’s Act 2000 fortified carers’ rights, giving them an entitlement to receive services in addition to an assessment. This entitlement exists even if the person being cared for refuses assessment or services for themselves. However, the nature of these services was unspecified, leaving this to the interpretation of local authorities.

The Carers (Equal Opportunities) Act 2004 builds on existing legislation by trying to ensure that carers do not become disadvantaged because they provide care. There are

three changes of importance. This first is that local authorities have a duty to inform carers of their right to an assessment of their needs. The second is that when conducting a carer's assessment, local authorities must consider whether the carer currently undertakes work, education, training or leisure activities or wishes to do any of these. Finally, the promotion of better collaborative working between local and other authorities with respect to planning and provision of services is advocated to provide a more coherent service for carers.

The National Service Framework for Mental Health (Department of Health, 1999b) has a separate standard (Standard 6) about carers. This asserts that all those providing care for individuals within the Care Programme Approach should have an assessment of their caring, physical and mental health needs at least annually. The National Service Framework for Older People (Department of Health, 2001) refers to carers throughout and carers are mentioned with respect to stroke. In particular, there is emphasis on carers' needs being considered as an integrated part of the way in which services are provided for older people. This document also asserts that carers should receive person-centred care and offered information, advice and practical help to support them.

The National Service Framework for Long-term Conditions (Department of Health, 2005) has a quality requirement concerning the provision of, and access to, support and services for carers of people with long-term neurological conditions. These services should recognise the needs of the carer in terms of their role as carer and in their own right.

The publication of these documents strongly suggests that carers have risen in the Government's agenda. Although carers were initially seen to require support with respect to their caring role alone, their own needs and entitlements have been increasingly acknowledged.

Carers are particularly important because they can play a significant role in supporting the patient in terms of their physical and emotional well-being. Following discharge from hospital, many stroke survivors return home with care and support being provided by family members. Given the potentially profound and diverse effects of stroke on survivors, their needs when they return home can be substantial. They may require help with personal care (e.g. washing, dressing); physical activities (e.g. walking, transfers); domestic tasks (e.g. meal preparation, housework); paperwork or financial matters (e.g. writing letters, paying bills); managing cognitive difficulties (e.g. orientation, remembering to take medication); communication (e.g. due to language difficulties) and emotional support (e.g. adjustment to the consequences of physical disability, cognitive difficulties, changes in role). These tasks require significant resources from the carer and there may be little time between the sudden onset of stroke and discharge from hospital for the carer to acquire all of these resources (Hankey, 2004).

Stroke survivors discharged from hospital depend on informal carers for practical and emotional support (Dennis, O'Rourke, Lewis, Sharpe & Warlow, 1998). This can help stroke survivors to be maintained in the community (Dennis et al., 1998), subsequently easing demands placed on services. Carers can also play a vital role in the stroke survivor's rehabilitation (Forsberg-Warleby, Moller & Blomstrand, 2001).

#### **4. The Impact of Stroke on Carers**

The physical and, to a lesser extent, emotional outcomes of stroke survivors are well known, yet the emotional outcomes of carers of stroke survivors is notably less researched (Dennis et al., 1998). There have been numerous studies which have investigated the impact of stroke on the patient while, in comparison, the impact of stroke on carers has been underrepresented, with less consideration given to this area (Berg, Palomaki, Lonnqvist, Lehtihalmes & Kaste, 2005; Morrison, 1999).

However, there is wide agreement that carers of stroke survivors experience certain emotional responses or outcomes. One of the emotional outcomes most often studied is depression (Han & Haley, 1999). There have been numerous estimates of the prevalence of depression among stroke carers. Schulz, Tompkins & Rau (1988) found that this figure was 34% among stroke carers as measured by the Centre for Epidemiologic Studies Depression Scale, both at 3-10 weeks after the individual's stroke and 6 months post-stroke. Although this figure is the same at both time points, not all of those who were depressed at 3-10 weeks were the same people as those depressed at 6 months. This may suggest that there could be factors influencing depressive symptoms at different points in time. The prevalence of depressive symptomatology among stroke carers was found to be between 2½ to 3½ times higher than non-carer national samples of similar age (Schulz et al., 1988)

Berg et al. (2005) investigated depression among carers of stroke survivors at the acute phase (approximately 2 weeks after stroke) and at 6 and 18 months after stroke. Using the Beck Depression Inventory (BDI), with a score of 10 or more to indicate mild

depression, they found that 33% of all carers were depressed at the acute phase, 30% at 6 months and 30% at 18 months post stroke. Furthermore, they found significantly higher BDI scores among the spousal carers than among other carers across all three time points. The rates of depression in the carers were higher than those found among patients in an earlier study (Berg, Palomaki, Lehtihalmes, Lonnqvist & Kaste 2003). Among these patients, using the BDI with the same criteria of 10 points, rates of depression ranged from 23% to 29% across the 18 months after stroke (27% at acute phase; 23% at 6 months and 26% at 18 months post stroke). Based on interviews with a psychologist, 38% of spouses at 6 months and 29% at 18 months post stroke were considered to be exhausted (Berg et al., 2005). Details of how the psychologist determined exhaustion was not described but spouses who were identified as exhausted were, at both time points, more often depressed than those who were not.

Draper, Poulos, Cole, Poulos & Ehrlich (1992) compared carers of individuals who had stroke and dementia. They found that 52% of carers of stroke survivors showed distress, measured by a score of 4 or more on the General Health Questionnaire 30 item version (GHQ-30). Furthermore, there were no significant differences in levels of distress between the carers of those with stroke and dementia. Dennis et al. (1998) investigated emotional outcomes for stroke carers 6 months after stroke and found that 55% of carers showed indications of emotional distress (scoring 4 or more) as measured by the GHQ-30. Also, using the Hospital Anxiety and Depression Scale (HADS) with a recommended cut-off of 8/9, 17% and 37% showed symptomatology indicative of depression and anxiety respectively. At 1 year post stroke, Anderson Linto & Stewart-Wynne (1995) reported that 42% of carers showed emotional distress according to the

General Health Questionnaire 28 item version (GHQ-28), where a cut-off of 5 or more was employed. The authors also reported 30% of carers being classified as depressed and 44% of carers as anxious, according to cut-offs of 8 or more on the HADS.

Increases in anxiety and irritability in stroke carers have been reported by others (Wade, Legh-Smith & Langton-Hewer, 1986). Forsberg-Warleby et al. (2001) found that some key aspects of psychological well-being were poorer in spouses of stroke patients during the acute stages of stroke than in the general population. In particular, they found that spouses of stroke patients fared worse in the areas of anxiety, depressed mood, positive well-being, self control and vitality. Anderson et al. (1995) found that, at 1 year after stroke, 79% of carers reported emotional ill-health and disrupted social activities. They also found that 35% of carers reported negative effects on relationships in the family, including misunderstandings and tension. Other emotional reactions commonly experienced by stroke carers included fear, frustration, resentment, impatience and guilt (Anderson et al., 1995). Using the Nottingham Health Profile, Greveson, Gray, French & James (1991) reported that carers had more difficulties with respect to emotional reactions, sleep and social isolation compared to age/sex matched community controls.

Several studies have looked at the level of strain among carers of stroke survivors, using the Caregiver Strain Index (CSI). Blake & Lincoln (2000) reported that 37% co-resident spouses of stroke patients reported significant strain, although the sample they looked at were at different lengths of time after stroke. In a later study, Blake, Lincoln & Clarke (2003) reported that levels of strain among spouses at 3 months after stroke was 39% and at 6 months after stroke it was 40%. Others (Bugge, Alexander & Hagen, 1999)

have reported similar levels of strain in carers over the first 6 months post stroke, with a trend for the proportion to increase (25% at 1 month, 28% at 3 months and 37% at 6 months) over time. This could suggest that strain among spouses and other carers remains consistently high over time, or at least across the first 6 months after stroke. Furthermore, in a study of long-term outcome of patients and carers, Greveson et al. (1991) found that, at least 3 years after stroke, 30% of carers of stroke survivors showed marked strain (CSI score >6).

In summary, there appears to be agreement that there are high levels of certain emotional outcomes such as depression, distress, strain and anxiety in carers of stroke survivors. However, estimates of the prevalence of such outcomes have been variable. This variation could be partly attributed to different measures used to assess these outcomes, the sample of carers investigated and the time elapsed since stroke. Nevertheless, it is apparent that stroke carers are at greater risk of poorer emotional outcomes than non-carer populations. Most of the research has focused on emotional or psychological outcomes in carers of stroke patients (Low, Payne & Roderick, 1999). This leaves other aspects of quality of life neglected, including physical functioning, social relationships and the individual's environment. These areas need further investigation.

While emotional outcomes are recognised as problematic among carers of stroke survivors, there is perhaps less agreement concerning the factors that contribute to these. It remains difficult to understand which carers are likely to manage and which carers are likely to fare poorly and experience difficulties (Hodgson, Wood & Langton-Hewer, 1996). Blake & Lincoln (2000) comment that research looking at the characteristics of



the carer that could make them more vulnerable to strain and distress is required.

Indeed, there still exists many carers who experience psychiatric and physical illness that may be overlooked (MacLennan, 1998). Therefore, it seems appropriate to consider the literature that has explored the factors associated with poor outcomes in stroke carers.

## **5. Factors Associated with Poor Outcomes in Stroke Carers**

There has been some research investigating which carers of stroke survivors are most at risk, including studies examining factors associated with poor outcomes in stroke carers.

If we are able to identify the central variables contributing to poor outcomes in this group of carers, we may then be able to develop the most appropriate ways of targeting interventions. Identification of carers at risk early on could allow services to focus on prevention rather than cure or managing a crisis (Blake & Lincoln, 2000; Blake et al., 2003). This could directly benefit the carer, could have an indirect benefit to the stroke survivor and potentially ease burden on services. The lack of clarity concerning which carers are at most risk of poor outcomes indicates that it is also unclear which carers are most likely to benefit from effective interventions (Dennis et al., 1998). Therefore to be able to design effective interventions and target them at the most appropriate individuals, it is necessary to examine the factors related to poor outcomes in carers.

### ***5.1 Demographic Factors***

In terms of demographic factors, there appear to be no differences between male and female carers in terms of strain (Blake & Lincoln, 2000), depression (Thompson et al., 1990), distress (McClenahan & Weinman, 1998), social adjustment (Kinsella & Duffy, 1979) or with psychological well-being, view of the future and satisfaction with life

(Forsberg-Warleby et al., 2001). However, Forsberg-Warleby et al., (2001) noted an association between carer gender and satisfaction with own ability to self-care, finding that women were more satisfied than men. In another study (Dennis et al., 1998) female carers reported more anxiety than male carers. However, the authors suggested that this difference could just be a reflection of differences between male and females in the general population. No relationship between the gender of the stroke survivor and carer distress has been identified (McClenahan & Weinman, 1998).

The age of the carer has not been found to be related to carer depression (Thompson et al., 1990) or distress (McClenahan & Weinman, 1998). Forsberg-Warleby et al. (2001) did not find a relationship between the age of spouses of stroke survivors and spouses psychological well-being, view of the future and satisfaction with life. However, they did find a relationship between age and satisfaction with sexual life, with younger spouses being more satisfied than older spouses.

In the study described earlier, carried out by Berg et al. (2005), older stroke survivor age was reported to be an independent predictor of depression in carers at the acute stage. This was also an independent predictor in spouses, but not the carer group as a whole, at 18 months after stroke. The authors noted that the relationships between patient age and spousal depression became stronger over time. It should be noted that their study only examined carers/spouses of stroke survivors under 70 years old. Therefore associations between even older stroke survivors and carer/spousal depression are unknown. In contrast, Tompkins, Schulz & Rau (1988) found that those at greater risk of depression at 1 year follow-up were carers of younger stroke survivors. They suggest that this may

be related to differential occupational and economic ramifications, with milder disruptions for older stroke survivors who may already be retired. They also state that there might be greater anticipation of illness and disability among older individuals. These factors might account for increases in depression among carers of younger stroke survivors who may have expectations about their economic and occupational prospects and their levels of illness/disability. Although varying relationships have been found between stroke survivor age and depression, others have not found a relationship between stroke survivor age and strain in co-resident spouses (Blake & Lincoln, 2000) or distress in carers (McClenahan & Weinman, 1998).

Spouses of the stroke survivor have been found to be more depressed than non-spousal carers (Schulz et al., 1988). This was found 3-10 weeks after stroke but this was not a predictor of depression at 7-9 months after stroke. Others have found that the risk of depression was greater, at both 6 month and 1 year follow-up, when carers were married to the stroke survivor (Tompkins et al., 1988).

There could be several explanations for spousal carers being more depressed than non-spouses. One possibility may be that spouses are more likely than other relatives to reside in the same household as the stroke survivor, which could be an influential factor for depression. It is also possible that, for spousal carers, increased needs (e.g. physical, cognitive or emotional) of the stroke survivor could have a negative impact on reciprocal roles within the relationship. Aspects of the relationship that were perhaps previously shared, including everyday tasks, responsibilities, decision making and emotional support, may no longer be able to be shared in the same way as they were before the

stroke. Spouses may also be more affected because of possible changes in their sexual relationship. Furthermore, other relatives may obtain support from their spouses which may mediate the impact of caring, explaining why they might be less affected.

### *5.2 Time Since Stroke & Number of Strokes*

The length of time since stroke has not been found to be related to strain in co-resident spouses (Blake & Lincoln, 2000), depression in carers (Thompson et al., 1990) or distress in carers (McClenahan & Weinman, 1998). However, Kinsella & Duffy (1979) found that adjustment was poorer in spouses where there had been a longer time interval between the onset of stroke and the interviews that were carried out as part of the study. Where stroke survivors have had multiple strokes, carers have been found to be more depressed than those who have had only one (Thompson et al., 1990).

### *5.3 Time Spent Caring*

Bugge et al. (1999) found that the amount of time the carer spent with the stroke survivor and the amount of time they spent helping the stroke survivor (out of the time they spend with the stroke survivor) were both independently associated with carers' level of strain at 1, 3 and 6 months after stroke. At all of these time points, less time spent with the stroke survivor and more time spent helping them was related to increased strain. The authors suggest that carers at risk of greater strain are those who have to perform the tasks of caring within a busy schedule, yet do not normally spend time with the stroke survivor. An additional explanation could be that time spent with the stroke survivor, beyond the caring tasks alone, could have a mediating effect. For example, if

the carer and stroke survivor share time doing an activity unrelated to the caring role, this might help to reduce the strain experienced by the carer.

#### *5.4 Stroke Severity, Physical Disability and Functional Abilities of the Stroke Survivor*

In the study reported by Berg et al. (2005), stroke severity measured soon after stroke, using the Scandinavian Stroke Scale (SSS), was an independent predictor of carer depression in the acute phase after stroke but not at 6 or 18 months after stroke. The SSS includes ratings of consciousness; eye movement; arm, hand and leg motor power in the affected side; orientation; speech; facial palsy and also gait. However, the authors found that the Barthel Index, a measure of function in terms of basic activities of everyday living, correlated with both depression and stroke severity in this acute phase. Therefore, although stroke severity was found to be independently associated with depression, it is not possible to ascertain whether this was a direct relationship or whether it was mediated by functional disability.

One factor that is contentious in explaining emotional outcomes in carers is the degree of physical or functional disability of the stroke survivor. Blake & Lincoln (2000) noted that stroke survivors' disability was independently associated with strain in co-resident spouses. The authors assessed stroke survivor disability in terms of carer's perceptions of their extended activities of daily living, as measured by the Nottingham Extended Activities of Daily Living Index (EADL). In a later study, Blake et al. (2003) tested the ability of a previously generated logistic regression model to predict carer strain from three key factors. Among these three factors, which also included carer mood and negative affectivity as predictors, they looked at carer's perceptions of perceived patient

functional ability using the EADL. Unlike their previous study (Blake & Lincoln, 2000), which was cross-sectional in design, Blake et al. (2003) were able to look at these factors prospectively over a 6 month period. They found that assessments of EADL, together with carer mood and negative affectivity, at 3 months post stroke was 78% accurate at correctly predicting whether carers were under strain at 6 months post stroke. One potential problem with the assessment of functional abilities in these studies, which Blake et al., (2003) acknowledge, is that it reflects carers' perceptions of functional ability rather than what might be deemed as more objective or observed ratings. Hence, it might be more appropriate to conclude that they found that carer perceptions of stroke survivors' functional ability, rather than actual or objective functional ability, played a role in predicting carer strain. More research is needed to determine whether carer ratings of functional abilities are comparable with objective measures of this.

Others have also found a relationship between the physical impairment of the stroke survivor and carer depression (Thompson et al., 1990). Greater need for assistance has been found to be related to lower morale in carers (Purk & Richardson, 1994).

Some studies have found that changes over time influence the relationship between disability and carer outcomes. Wade et al. (1986) found that the patient's functional disability, assessed by the Barthel Index, was related to carer depression over the first year after stroke but not at 2 years post stroke. Depression in this study was assessed using the Wakefield self-assessment depression inventory. The authors reported that depression was not uncommon (28%) in carers of functionally independent stroke survivors at 6 months. In explaining the change in relationship between functional

disability and depression over time, Wade et al. (1986) proposed that carers of stroke survivors may be more distressed initially because greater disability, at this point, could bring concerns about the future, which may reduce over time.

Anderson et al. (1995) did not find a relationship between emotional illness in carers and the extent of the stroke survivor's physical disability. They reported a non-significant trend in the relationship between emotional distress and assistance with some specific activities of daily living (bathing, incontinence, feeding, grooming). Others have not found a relationship between physical disability (measured by the Barthel Index) and carer well-being (Hodgson et al., 1996), burden or distress (Draper et al., 1992).

The role of the severity of physical or functional disability as a determinant of poor carer outcome appears equivocal. Explanations for differences in findings between studies and over time could be related to differences in methodology, sensitivity of the measures used and the sample. The explanation provided by Wade et al. (1986), that carers might be more distressed initially because of concerns about the future, could account for change over time. An alternative reason for inconsistencies in findings might be that other factors, not measured in these studies, serve to mediate the relationship between physical/functional disability and carer outcomes.

### *5.5 The Presence of Aphasia in the Stroke Survivor*

Williams & Freer (1986) investigated the effects of aphasia on marital relationships from the perspective of spouses of stroke patients. They found significant differences between spousal reports of their perception of, and satisfaction with, their marriage

before and after stroke, with more negative perceptions after stroke than before. This finding was supported by Williams (1993) who reported that the way that spouses felt about various aspects of their relationship, compared with their expectations, had changed negatively from pre to post stroke. These findings were consistent across all three levels of aphasia severity identified in both studies. Hence, it did not appear that the severity of aphasia was a determinant of marital satisfaction. Since there was no examination of spouses of stroke survivors that did not have aphasia, it is not possible to compare spousal marital satisfaction between aphasics of any severity and non-aphasics. Both of these studies relied on retrospective reporting of marital satisfaction pre-stroke, which may not be an accurate reflection of actual pre-stroke marital relationships.

An early study (Kinsella & Duffy, 1979) investigated social adjustment in spouses of aphasic stroke survivors. They compared three groups including those with aphasia only, those with both aphasia and hemiplegia and those with hemiplegia only. They found that spouses of aphasic stroke survivors, who also had hemiplegia, had poorer overall adjustment than spouses of those who only had hemiplegia. They also noted that spouses of aphasics had poorer adjustment than non-aphasics in social and leisure activities and marital relationships.

In a review, Servaes, Draper, Conroy & Bowring (1999) concluded that caregiving burden is greater for carers of aphasic rather than non-aphasic patients but suggest that they do not have greater psychological morbidity. Other studies have not found a relationship between the presence of aphasia and spousal psychological well-being (Forsberg-Warleby et al., 2001) or carer distress (McClenahan & Weinman, 1998).



### *5.6 Cognitive impairment in the Stroke Survivor*

There has been little research concerning the role of the stroke survivor's level of cognitive ability as a factor influencing carer outcomes. Dennis et al. (1998) found that carers had a tendency to have poorer scores on the GHQ-30 if the stroke patient was unable to complete a self-report measure (GHQ-30) compared to carers of stroke survivors who were able to complete this measure. However, this finding did not reach significance. Furthermore, it is questionable whether stroke survivor's ability to complete a self-report measure is an accurate means of assessing cognitive ability.

Using the Mini Mental State Examination, a screening measure for cognitive impairment, Anderson et al. (1995) found no differences between carers defined as cases and non-cases of emotional distress. Other studies that have used more rigorous neuropsychological assessments of stroke survivors (e.g. subtests from the Wechsler Adult Intelligence Scale and Wechsler Memory Scale) have not found a relationship between cognitive impairment and carer depression (Berg et al, 2005).

### *5.7 Behavioural Problems in the Stroke Survivor*

Anderson et al. (1995) found a trend towards a higher level of abnormal behaviour in stroke survivors whose carers were defined as cases of emotional distress compared to carers not defined as distressed. Abnormal behaviour was measured by the Social Behaviour Assessment Schedule and caseness was determined by carers' scores on the HADS or GHQ-28. However, the trend that was found just failed to reach significance, although it was one of the strongest characteristics in their study associated with distress.

In another study, behavioural and mood disturbance in stroke survivors aged 60 or over were correlated with carer burden and distress (Draper et al., 1992).

### *5.8 Emotional Status of the Stroke Survivor*

The stroke survivor's emotional status has been suggested to be associated with carer outcomes. Patient depression has been linked to carer depression within 1 year post stroke but not at 2 years (Wade et al., 1986). Morale of stroke survivors has been found to be positively correlated to spousal morale (Purk & Richardson, 1994). As mentioned before, Draper et al. (1992) found that, along with behavioural disturbance, mood disturbance in stroke survivors aged 60 or over was correlated with carer burden and distress. In their longitudinal study, Berg et al. (2005) found no relationship between patient depression at the acute stage (approximately 2 weeks post stroke) and carer depression at 2 weeks, 6 months or 18 months post stroke. They obtained the same non-significant findings when examining spouses only, rather than carers as a whole. The only relationship they found between patient and carer depression was when they were both assessed at 18 months post stroke.

### *5.9 Emotional Status of the Carer*

Blake & Lincoln (2000) investigated factors associated with strain in co-resident spouses of stroke patients. They found that carer mood, as assessed by the General Health Questionnaire 12 Item Version (GHQ-12), was the most important factor independently associated with strain. They observed that strain was associated with lower self-esteem, decreased positive affectivity and increased negative affectivity. Negative affectivity, as measured by The Positive and Negative Affectivity Schedule, was independently

associated with carer strain. As mentioned earlier, carer mood and negative affectivity at 3 months post stroke, along with carer ratings of patient functional abilities, was 78% accurate at predicting carer strain at 6 months post stroke. Carer depression at the acute stage (approximately 2 weeks post stroke) has been found to be an independent predictor of carer depression at 6 and 18 months post stroke (Berg et al., 2005). Others have found that depressive symptoms in carers soon after the stroke, was likely to predict those at risk of depression both 6 months and 1 year later (Tompkins et al., 1988).

#### *5.10 Carer's Physical Health*

One study found that carers' physical health, reported by carers at 3 months post stroke, was a significant predictor of carer well-being at 12 months post stroke, as measured by the General Well-Being Index (GWBI) (Hodgson et al., 1996). However, as the authors acknowledge, the means of assessing carer health was established from carer responses to simple non-standardised questions rather than more objective measures.

#### *5.11 Perception of Recovery*

In their longitudinal study, Wade et al. (1986) found that carers' perception that the stroke survivor had made a poor recovery was associated with greater carer depression at 6 and 12 months post stroke. This relationship was not found at 2 years post stroke. The relationship between carer perception of recovery and depression could suggest that carer beliefs play an important role in their emotional outcomes. However, despite being a longitudinal study, these associations were only found at the same points in time. Associations between earlier perception of recovery and later depression were not reported. It is therefore possible that carers' negative mood state influenced their

perceptions of recovery. It is also feasible that carer perceptions of recovery represented a realistic perception that the stroke survivor's recovery was poorer. However, the authors did not examine whether carer perceptions were related to functional ability and therefore it is difficult to draw clear conclusions.

Another problem is concerning the means of assessing perception of recovery. The authors used a 15cm line with one end representing 'the worst he was after the stroke' and the other end representing 'as he was before the stroke'. The use of a single question such as this with no other means of assessing perception of recovery might leave the reliability and validity of this finding questionable.

#### *5.12 Social Networks and Support*

Tompkins et al. (1988) suggested that social networks are a factor related to carer depression. They found that carers at risk of depression both at 6 months and at 1 year follow-up had fewer people in their social networks before the stroke occurred than those not at risk. By the 6 month follow-up both groups had comparable numbers of people in their social network and therefore the authors suggest that the numbers in carers' networks after stroke did not contribute to this finding.

Blake & Lincoln (2000) noted that strained carers perceived themselves as having less emotional and practical support than those who were not strained. This finding was related to a greater discrepancy between carers' perceptions of their ideal and actual levels of both emotional and practical support. There was no relationship between strain and ideal levels of emotional or practical support.

### *5.13 Carer Appraisal of Caregiving Stress & Coping*

Carers' appraisal of caregiving stress at 3 months post stroke was found to be the most significant predictor of carers psychological well being at 12 months post stroke, as measured by the GWBI (Hodgson et al., 1996). However, this study based the assessment of carer appraisal of caregiving stress on a single question that used a 4-point likert scale, leaving the validity of the finding questionable.

Non-confronting coping has been found to be associated with stress and depression in carers of stroke survivors and older confused people (Matson, 1994). Non-confronting coping referred to indirect coping strategies or avoidance (e.g. keeping busy doing anything to avoid thinking of caring). Those more involved in this type of coping had higher levels of stress and depression. Quality of coping was also related to levels of stress and depression in carers (Matson, 1994). Carers' quality of coping was assessed by the responses they made to a video that depicted specific 'hassles' that they might experience. Carers described how they coped with the 'hassles' that they had identified as experiencing in their own situation. They were rated on how well their description showed empathy, respect, sensitivity and met the needs of the carer and care recipient. Those who performed better on this task had lower stress and depression scores.

While coping appears to be relevant to carer outcomes, the measures of coping used by Matson (1994) were not standardised and reliability and validity is unknown. Despite this weakness, using videos and analysing carers' descriptions of their management of specific situations could provide a more ecologically valid means of assessing coping. However, a problem with the study was the inclusion of both carers of stroke survivors

and older confused people. Older confused people included those with Alzheimer's disease and Multi-Infarct Dementia. Therefore it is not possible to assess whether such findings would have occurred in a stroke population alone.

In summary, there have been numerous studies attempting to identify the key determinants of poor emotional outcomes in carers of stroke survivors. The determinants explored in these studies include demographic factors, stroke/illness, stroke survivor and carer characteristics and also factors such as perception of recovery, perceived social support and coping. Some have been consistently identified as important contributors to stroke carer outcomes while others have shown inconsistencies. However, some studies have methodological weaknesses such as small sample sizes, non-standardised and psychometrically weak measures and statistical analyses using correlation only. These and other methodological weaknesses may account for some of the variability in the findings reported.

Furthermore, studies have used different definitions of 'carer'. Some have examined spouses only (Blake et al., 2003); some spouses and other family members (Schulz et al., 1988) and some have included family and non-family members (Thompson et al., 1990). There are other studies that have not provided clear definitions of 'carer' (Greveson et al., 1991), yet others have given specific definitions (Hodgson, et al., 1996; Wade et al., 1986). In addition, selection of participants has varied between studies. Some are based on stroke survivors who have been referred to rehabilitation services (Draper et al., 1992) while few have looked at carers of stroke survivors in the community (Anderson

et al., 1995). This contributes to additional difficulties when making comparisons between studies and reduces their generalisability.

Although several studies have employed longitudinal designs, many have used cross-sectional designs. This generates difficulties when attempting to infer meaning from the relationships found. For example, for the relationship between coping and carer depression, it could be that coping affected carer mood, carer mood affected coping or the effect was bi-directional. Alternatively, some other variable not measured was affecting the relationship between the variables, acting as a mediator or moderator. Among longitudinal research, certain variables associated with carer depression have varied over time (e.g. Schulz et al., 1988; Wade et al., 1986). This suggests that, at different stages of the stroke survivors' recovery, some factors are more pertinent than others in accounting for carer outcomes.

Different measures of emotional outcome have been used between studies, creating difficulties when making comparisons. In addition, as mentioned before, many studies have focused on emotional outcomes in carers and have not looked at broader outcomes such as carers' quality of life.

Most research investigating the impact of stroke on carers has not focused on carer's perceptions of the stroke patient's illness or on the effects that such perceptions may have on carer outcomes. The contribution of social cognitions has been neglected yet these may serve an important role. For example, they may function as direct determinants of outcomes, or may represent mediators, which could potentially explain

some of the inconsistent findings in the studies described. Furthermore, social cognition variables may be more modifiable than other factors (e.g. the severity of the stroke, type of relationship) and therefore could offer promising avenues for intervention. Although the studies discussed may provide an increased awareness of some of the factors contributing to carer outcomes, we have little knowledge of the underlying mechanisms by which these factors may be involved. Few of the studies mentioned have explored the role of theoretical frameworks in explaining their research findings. Understanding the theoretical frameworks that could explain why some people do well while others fare more poorly may help in the development of useful psychological interventions.

## **6. Theoretical Frameworks to Understand Carer Outcomes**

There are several theoretical models which may increase our understanding of carer outcomes. Therefore it is important to explore some of these theoretical frameworks and their potential contribution in accounting for poor outcomes in carers of stroke survivors. This is particularly important because these models may suggest other variables that have not sufficiently been considered and may provide predictions about how certain variables might relate to one another and to outcomes.

### *6.1 Pearlin's Stress Process Model*

One model that can be applied to carer stress is The Stress Process Model (Pearlin, Mullan, Semple & Skaff, 1990), developed primarily in the context of explaining stress in caregivers of individuals with dementia. There are four dimensions to the model. The first, background and contextual factors, includes the individual's personal history,



family context, cultural factors and socioeconomic status. These can influence the way that caring is carried out in a myriad of different ways (Zarit & Edwards, 1999).

Stressors, the second dimension, consist of three types; primary stressors, secondary role strains and secondary intrapsychic strains. Primary stressors are events or actions directly related to the person's disability and the associated caring tasks (Zarit & Edwards, 1999). This might include behavioural difficulties in the care recipient or providing help with their care needs. The model distinguishes between objective and subjective primary stressors. Objective stressors refer to the tasks that the carer is actually involved in (e.g. responding to behaviour or helping with personal care). Subjective stressors relate to the carers experience of the immediate impact of these stressors (e.g. feelings of overload). The second type of stressor, secondary role strains, refers to the impact of caregiving on other domains of the carer's life, such as relationships or family conflicts, disruption of work or economic strains. The final type of stressor, secondary intrapsychic strains, refers to the impact of caring on the carer's appraisal of the tasks that they carry out and of themselves (e.g. self-esteem, carer competence, personal gain).

The third dimension of the model refers to mediating resources which can influence the impact of the stressors on outcomes. Two common resources are coping and social support. The final dimension represents the outcomes which result from the background and contextual factors, the three dimensions of stressors and the mediators.

The stress process model has primarily been examined in the context of dementia. In applying this model, Grafstrom, Fratiglioni & Winblad (1994) investigated the effects of background and contextual factors and the primary stressors to understand burden in relatives of those with dementia. They reported that being a female carer and behavioural problems in the person with dementia were related to greater carer burden. Long duration of the condition and increased difficulties in activities of daily living, in the mild phase of dementia, were also related to greater carer burden.

In reviewing the literature about carers of people with dementia, Zarit & Edwards (1999) noted only small associations between objective primary stressors and carer outcomes. They stated that subjective primary stressors (e.g. increases in role overload) appeared to result in greater emotional distress than objective stressors. With respect to secondary role strains, they indicated that studies have shown that caring can impact on family relationships, work and also leisure/social activities, although individual differences existed. Although this review illustrates how aspects of the stress process model are important in outcomes of carers of those with dementia, it does not necessarily explain how the dimensions interact or follow on from one another.

There does not appear to have been any explicit application of the stress process model to understand stroke carer outcomes. However, some dimensions of the model have been studied, such as demographic variables (background and contextual factors) and level of disability (primary stressor). Nevertheless, this research does not explain the processes involved in poor carer outcomes. Central to the stress process model is the contribution of the three types of stressors towards outcomes. Background and

contextual factors are seen as influential and resources, such as coping and social support, are potential mediators. This is a rather static model but situations and circumstances are constantly changing in the caring role. Therefore a more dynamic and flexible model is needed.

## *6.2 The Cognitive Appraisal Model of Stress & Coping*

Lazarus & Folkman (1984) proposed a model of stress and coping which offers an alternative, although not incompatible, model for understanding the impact of stroke on carers. The model describes how stress can be determined by primary appraisals, secondary appraisals and coping. Primary appraisal occurs in response to a potential stressor. It involves the individual appraising the stressor in terms of whether it represents threat, harm, loss or challenge, and the extent of this, or whether it is seen by the individual as beneficial or neutral. Secondary appraisal follows an individual's primary appraisal. The individual, who has perceived the potential stressor as threatening, harmful or challenging, evaluates whether they believe they have the resources to deal with the stressor. These two appraisal processes can determine the coping strategies utilised by the individual.

Coping describes the individual's attempts to modify the demands of something stressful or to manage emotional effects. It is an evolving, rather than static, process that involves appraisal and reappraisal in changing situations or in response to the success or failure of the chosen means of coping. Lazarus & Folkman (1984) distinguished between problem-focused and emotion-focused coping. Problem-focused coping refers to the strategies adopted by the individual to reduce demands of the situation or stressor,

or to increase their resources for managing it. This usually occurs when the individual believes that either of these is modifiable. Emotion-focused coping refers to the efforts an individual makes to alter the emotional response to the stressor. This usually occurs when the individual does not believe that it is possible to modify either the stressor or their resources to deal with the demand.

This model of stress and coping has a clear focus on the process of appraisal. The coping strategies employed by the individual may be of a cognitive or behavioural nature. Considerable research has adopted this model in explaining how individuals cope with chronic conditions, for example, in breast cancer (Gallagher, Parle & Cairns, 2002), psoriasis (Hill & Kennedy, 2002) and spinal cord injury (Kennedy et al., 2000).

Using this model of stress and coping in carers of stroke survivors, one might suggest that the carer first makes an appraisal of threat, harm, loss or challenge presented by the stroke or an aspect of the stroke. The carer may then examine their resources to deal with this, which guides their selection of coping strategy. Some of the literature discussed earlier appears consistent with aspects of the stress and coping model. For example, the finding that carers' appraisal of caregiving stress was a predictor of carer psychological well being (Hodgson et al., 1996) suggests an important role of appraisal. However, there was no exploration of the separate contribution of primary and secondary appraisals. Instead, a single question on a 4-point likert scale asked carers whether they found caregiving stressful. Each possible response pertained both to the degree of stress and whether the carer thought they could cope (e.g. 'quite stressful – but I can cope'). Hence, carer appraisal of threat and resources were not examined

separately. Within the stress and coping model, the literature presented earlier concerning social support and networks could suggest that social support might be conceptualised as a coping resource.

Concerns have been mentioned that there is insufficient empirical support to claim that coping explains a substantial amount of the variance in outcomes in chronic illness (Kaptein et al., 2003). Fortune, Richards, Griffiths & Main (2002) commented that coping has been seen as a weaker predictor of psychological adjustment in chronic illness. One possibility is that a lack of strong findings may be attributed to psychometric properties of measures that assess coping. Coyne & Racioppo (2000) assert that differences in goals and agendas across situations and persons have not been adequately addressed. They argue that the current coping literature readily assumes that individuals' goals are to reduce distress rather than to attain other goals. Hence, more attention needs to be given to the meaning of the stressors which might determine the coping efforts an individual adopts.

### *6.3 Family Systems Illness Model*

One systemic framework for understanding family challenges in illness and disability is the family systems illness model (Rolland, 1994; Rolland, 2003). This suggests that the psychosocial demands of the condition and the family style of functioning and their resources influence coping and adaptation. There are three important integrating dimensions; psychosocial typologies of illness, developmental phases over time and family system variables.

The psychosocial types of illness refer to onset (acute, gradual), course (progressive, constant, relapsing/episodic), outcome (fatal, shortened life span, possible sudden death, no effect on longevity) and incapacitation (none, mild, moderate, severe). The illness is characterised by these components to generate clusters of illnesses which have similar psychosocial demands. The degree of unpredictability about the condition overlays the four variables described. Using this framework, stroke is viewed as being of sudden onset, of constant course, possibly fatal and incapacitating. This typology, connected with the condition, is likely to be associated with specific practical and affective psychosocial demands for the individual and family across the life cycle.

The developmental time phases of illness are also important. Illnesses change over time and chronic illness needs to be viewed developmentally across crisis, chronic and terminal stages. Different phases represent different challenges and tasks for the individual and family. There are critical transition periods where families may need to adopt new structures of dealing with the situation. Family variables within the model include family and individual life cycles; multigenerational patterns of coping with illness and loss; belief systems and also ethnicity, spirituality and culture.

This model provides a means of integrating the psychosocial types and phases of illness with family variables and with interactions of the illness, individual and family. It also allows an understanding of family adaptation to chronic illness (Rees, Wilcox & Cuddihy, 2002). However, it might be suggested that it takes a focus away from individual processes, with less attention directed at explaining the mechanism by which illness might impact on an individual family member.

## **7. Illness Perceptions**

### ***7.1 Leventhal's Self-Regulation Model***

One model that may offer a framework for understanding outcomes in carers of stroke survivors is Leventhal's self-regulation model (SRM) (Leventhal et al., 1997; Leventhal, Brissette & Leventhal, 2003; Leventhal, Meyer & Nerenz, 1980). The model suggests that individuals form representations of their illness in response to a health threat which guides their coping and adaptive outcomes. The SRM defines more specifically the stimuli that might be related to health threats and coping, than the stress and coping model (Kaptein et al., 2003). While the SRM focuses on individual processes, it also considers the wider system and is dynamic, emphasising that beliefs change over time.

The SRM asserts that individuals construct both cognitive and emotional representations of their illness, which are based on their interpretations of key sources of stimuli. These sources may include information that has been accumulated and integrated by the individual. This can be through previous social and cultural sources; information provided by external sources and through the persons own experiences of the illness. Examples include media stories about the illness; what a parent or teacher has told the individual and witnessing the illness in another person. It could also include the experience of symptoms and illness in the individual themselves and their experience of the effectiveness of managing the illness. These stimuli include past and current information which may be supplemented or modified throughout the person's life-span.

Individuals are active processors of disease or illness related information. In an effort to make sense of these stimuli, the individual forms a representation of their illness. One

component of this representation refers to the cognitive representations, also widely known as cognitive illness perceptions. It has been proposed that there exist five key dimensions of cognitive illness perceptions around which individuals cluster their beliefs. These are *identity*, *timeline*, *cause*, *consequences* (Leventhal et al., 1980) and *control/cure* (Lau & Hartman, 1983). The first, *identity*, refers to the persons ideas about the label and the associated symptoms of the illness. *Timeline* relates to the perceived course that the illness takes or the duration of the illness. The dimension *cause* pertains to the individual's beliefs about the reason for the onset or cause of the condition. The *consequences* dimension describes beliefs concerning the expected outcome or implications of the condition. Finally, *control/cure*, denotes the beliefs about the extent to which the condition is controllable or curable. Evidence has been provided for the existence of these dimensions (e.g. Hagger & Orbell, 2003).

These five dimensions refer to the content of cognitive illness perceptions. Leventhal et al. (1997) stated that they are not independent dimensions but function as sets, whereby patterns of identity, timeline, cause, consequences and control/cure vary according to the illness (e.g. flu = coughs, stuffed nose, fever and fatigue symptoms; viral cause; 2-10 days duration; will go away by itself; disrupts daily life).

An important part of the dynamics of the model is the bi-level hypothesis, that is, within each cognitive illness perception there are two levels, abstract and concrete sources of information (Leventhal et al., 1997). The abstract, conceptual level refers to the linguistic codes in semantic memory (e.g. 'I have a heart condition') while the concrete level pertains to the perceptual aspects of the illness (e.g. the experience of palpitations).



Furthermore, the SRM indicates that these two levels are linked, often referred to as the symmetry rule. For example, individuals with a specific label or diagnosis (abstract level) will often search for symptoms (concrete level) and individuals with symptoms will often seek a label or diagnosis.

It is proposed that the cognitive illness perceptions guide the coping strategy or behaviour selected and used by the individual, which leads to certain outcomes (e.g. in terms of disease state, physical functioning or psychological well-being). The cognitive illness perceptions may also lead directly to these outcomes without coping as a mediator. The coping strategies and outcomes are then appraised by the individual. This may lead to modifications of the incoming stimuli, the representations and the choice of coping strategy.

Emotional illness representations (or emotional responses) of the incoming stimuli also exist. These are in parallel to the cognitive illness perceptions but can interact with them. Just as cognitive illness perceptions guide coping, outcomes and appraisal, emotional representations guide coping strategies to deal with the emotional reactions, which lead to outcomes and appraisal of coping. The SRM is dynamic and flexible through the process of appraisal.

## *7.2 Illness Perceptions in Patients and Outcomes*

Many studies have applied Leventhal's SRM in their investigations of illness perceptions in patients with chronic conditions. These studies have often focused on the contribution of illness perceptions in patient outcomes. Among many of the conditions

that have been examined in patients are multiple sclerosis (Jopson & Moss-Morris, 2003), rheumatic disease (Pimm & Weinman, 1998; Scharloo et al., 1998), chronic obstructive pulmonary disease (Scharloo et al., 1998), diabetes (Edgar & Skinner, 2003), cardiovascular disorders (Petrie, Weinman, Sharpe & Buckley, 1996; Whitmarsh, Koutantji & Sidell, 2003), epilepsy (Kemp, Morley & Anderson, 1999), Huntington's disease (Helder et al., 2002), Addison's disease (Heijmans, 1999), psoriasis (Fortune et al., 2002; Scharloo et al., 1998), irritable bowel syndrome (Rutter & Rutter, 2002) and chronic fatigue syndrome (Heijmans, 1998).

Many of these studies have found important relationships between illness perceptions and patient outcomes. Jopson & Moss-Morris (2003) reported that illness perceptions among those with multiple sclerosis played a significant role in adjustment to their condition. They found that patient's illness perceptions accounted for more of the variance than illness severity in social dysfunction, fatigue, anxiety, depression and self-esteem.

In their investigation of irritable bowel syndrome, Rutter & Rutter (2002) found that certain illness perceptions were strong independent predictors of outcomes. They also found that some coping strategies served as mediators between some illness perceptions and outcomes. Path analysis showed that beliefs concerning few serious consequences of the condition and feelings of control over the illness both had direct relationships with greater quality of life and greater satisfaction with health. Perceptions of more serious consequences were directly related to increased anxiety and depression. Fewer external causal beliefs were directly related to more satisfaction with life and psychological

causal beliefs were directly related to increased anxiety. In addition to these direct relationships, specific aspects of coping also mediated the effect of some of the perceptions on outcomes. For example, acceptance mediated the effect of consequences on quality of life, with those reporting fewer consequences being more likely to accept the illness and have greater quality of life. Negative effects were also found in terms of coping. For example, venting emotions mediated the effect of two illness perceptions (psychological causal belief and serious consequences) on anxiety. Furthermore, they found that some aspects of coping had direct relationships with depression.

The role of illness perceptions in patient outcomes is particularly emphasised in studies which have found that illness perceptions play a stronger role than coping. Illness perceptions were reported as stronger predictors of vitality, physical functioning and social functioning than coping, in those with chronic fatigue syndrome, although coping did still contribute to adaptive outcomes (Heijmans, 1998).

The studies described above represent some of the research findings concerning the relationship between illness perceptions, coping and outcomes. In these examples, specific relationships have been found between cognitive illness perceptions and coping and also between cognitive illness perceptions and outcomes. Furthermore, some of the studies have found that coping mediates the effect of cognitive illness perceptions on outcomes. Hagger & Orbell (2003) conducted a meta-analytic review, concluding that there are predictable relationships between cognitive illness perceptions and coping and between cognitive illness perceptions and outcomes. These predictable relationships have been found across studies of patients with a range of chronic illnesses.

Much of the research investigating illness perceptions has been stimulated by development of the illness perception questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996). This has provided a useful means of assessing illness perceptions in a standardised way and has been used in studying patient's illness perceptions in many conditions. A revised version of the illness perception questionnaire (IPQ-R) (Moss-Morris et al., 2002) has been developed. This incorporates important components derived from the SRM that were overlooked in the original version of the questionnaire, including emotional representations.

The application of the SRM has provided an increased understanding of the role of illness perceptions in patient outcomes. This is not restricted to patient groups and a growing body of literature is turning attention towards illness perceptions in other groups.

### *7.3 Illness Perceptions in Carers/Family Members*

There appear to be an increasing number of studies investigating illness perceptions in carers or family members of patients, most notably among partners. This is perhaps a reflection of an increased need to look at the wider context of chronic conditions and not just the individual who has the condition.

Heijmans, de Ridder & Bensing (1999), in a cross-sectional study investigating chronic fatigue syndrome and Addison's disease, examined the influence of dissimilarity in patients and spouses illness perceptions on coping and adaptive outcomes. They reported some divergent beliefs between patients and spouses. For example, spouses of

patients with chronic fatigue syndrome and Addison's disease were more pessimistic about the timeline of the condition than the patients. There also appeared to be inconsistent findings about the impact of spousal beliefs. When spouses of those with chronic fatigue syndrome were more positive about the timeline of the condition, patients showed more favourable outcomes. In contrast, when spouses of those with Addison's disease minimised the identity and consequences of the condition and were more positive about the timeline, patients functioned more poorly on measures of adaptive outcome.

In a prospective study examining causal attributions in patients and spouses of first time myocardial infarction, Weinman, Petrie, Sharpe & Walker (2000) found that spousal attributions of poor health habits were associated with improvements in patients' exercise level at 6 months.

In a later prospective study, Figueiras & Weinman (2003) examined whether similar patient and spouse perceptions of myocardial infarction predicted recovery. When patients and spouses had similar positive perceptions of the identity and consequences dimensions, patients showed better physical, psychological and sexual functioning and there was less impact of the myocardial infarction on social and recreational activities. Furthermore, similar positive perceptions were associated with reduced levels of disability in patients and similar positive cure/control beliefs were associated with greater dietary changes in the patient. Similar negative perceptions were associated with poorer patient outcomes. However, the authors found little differences in patient outcomes between dyads that had congruent positive perceptions and dyads where one

person had a positive representation and the other had a negative one. The quality of marital functioning was not associated with the extent to which dyads beliefs were congruent or divergent. These studies may have important implications in terms of the contribution of spousal or carer illness perceptions on patient outcomes.

In addition to studies examining congruency between patient and spousal illness perceptions, others have specifically investigated the role of carers' illness perceptions in both patient and carer outcomes. Barrowclough, Lobban, Hatton & Quinn (2001) used a modified version of the IPQ to investigate the illness perceptions of carers of patients with schizophrenia. There were two main components to the modification. The first was to re-word the IPQ so that it was from the carer's perspective (e.g. 'their illness' instead of 'my illness'). The second modification was to examine carers' control/cure and consequences beliefs from the perspective of the carer and the patient (e.g. 'their illness has major consequences on my life' and 'their illness has major consequences on their life').

Barrowclough et al. (2001) found that specific dimensions of illness perceptions were related to carer functioning, patient functioning and the patient-carer relationship. More precisely, they reported that carer perceptions of greater perceived negative consequences for the patient was related to greater carer distress. Greater perceived negative consequences for the carer were related to adverse outcomes in carers, including distress, depression and subjective burden. Carer perceptions of a stronger illness identity (more symptoms) were related to greater levels of carer depression. Among the relationships between illness perceptions and patient functioning, carers'

perception of a more chronic timeline was associated with a longer duration of patient illness, greater symptom severity and less adaptive functioning. A stronger illness identity was related to greater symptom severity and poor social functioning.

Roberts & Connell (2000) examined illness perceptions in relatives of people with Alzheimer's disease. Their study primarily examined the perceptions that relatives had about the disease and they investigated the characteristics influencing these perceptions. They found that some relatives had misconceptions which might potentially lead to adverse outcomes. For example, 20% of relatives were unaware of the existence of means to alleviate symptoms. They suggest that consequences of such beliefs could be that these relatives do not pursue means to alleviate symptoms for the person who has Alzheimer's disease. They also found that 19% thought that significant memory loss was part of normal ageing. Subsequently these individuals might not pursue a medical opinion if experiencing such difficulties themselves. A further finding was that almost a third of relatives believed there may be a cure within 5 years. As the authors state, this level of optimism might raise expectations about the outcome for the person they are caring for which are unlikely to be realistic. Although this was a preliminary study and did not examine the impact of illness perceptions on outcomes, Roberts & Connell (2000) demonstrated that illness perceptions may provide an insight into the understanding that relatives have of Alzheimer's disease.

Currently, it appears that only one study (McClenahan & Weinman, 1998) has looked specifically at illness perceptions in carers of stroke survivors. The study aimed to explore determinants of carer distress in non-acute stroke, examining illness perceptions

and coping as possible determinants. Other variables examined were demographic factors, characteristics of the stroke survivor (e.g. functional disability, cognitive functioning) and characteristics of the carer (e.g. self-efficacy, social support). Through multiple regression analyses, the authors found that the illness perception of timeline, generalised self efficacy and two coping strategies of venting and suppression explained a large amount of the variance of carer distress. Those perceiving the timeline to be longer had greater levels of distress and those who suppressed competing activities or focused on and vented their emotions were more distressed.

In line with other research, this study did not examine other outcomes in carers, such as quality of life. Furthermore, this study was carried out before the publication of the IPQ-R, which has additional components and stronger psychometric properties. In particular, the inclusion of emotional representations, which have not been studied as extensively as cognitive illness perceptions, might potentially have an important role in understanding outcomes. For example, in the study carried out by McClenahan and Weinman (1998), one might hypothesise that venting of emotions (an emotion-focused coping strategy) could have been explained by carers' emotional representations of the illness. This is speculation but it could be fruitful to investigate the contribution of emotional representations towards coping and outcomes.

In addition, McClenahan & Weinman (1998) did not appear to use the two parallel versions of any of the illness perception dimensions that Barrowclough et al. (2001) had used in their study. It might, for example, be useful to have a greater understanding of



not only the carers' perception of the consequences for the stroke survivor but also for themselves. One might be more associated with poor outcomes than another.

In summary, there are a range of theoretical frameworks that might be useful in understanding poor outcomes in carers of stroke survivors. The SRM may provide a theoretically strong means of investigating illness perceptions in carers of stroke survivors. This may increase our understanding of how these perceptions may contribute to coping and specific outcomes such as distress and poor quality of life. There has been a growing body of literature investigating the role of illness perceptions in patient outcomes and more recently the model has been applied to investigations of illness perceptions in carers.

## **8. Summary**

A review of the literature concerning carers of stroke survivors suggests that these carers are at risk of poor emotional outcomes, including depression, distress, strain and anxiety. However, areas such as quality of life have been neglected. Attempts have been made to establish the factors that are associated with poor outcomes, including demographic variables and characteristics of both the stroke survivor and the carer. Our ability to understand which factors are most likely to be associated with poor carer outcomes may allow us to target interventions. While some factors have been more widely accepted as related to carer outcomes, others have remained contentious. Methodological weaknesses may account for some of the inconsistent findings in the literature.

Some theoretical frameworks that may allow us to understand carer outcomes have been explored including Pearlin's stress process model, the cognitive appraisal model of stress and coping, the family systems illness model and Leventhal's SRM. The strengths of the SRM in comparison to the other frameworks have been discussed. A growing number of studies have used the SRM to explore the relationship between illness perceptions, coping and outcomes in patients in a range of chronic illnesses or conditions. The model has also been applied to carers of patients with chronic illnesses or conditions. Carer illness perceptions have been found to be associated with both patient and carer outcomes.

With the exception of one study (McClenahan & Weinman, 1998), there have been no other studies which have used the framework of the SRM to understand illness perceptions and their relationship to coping and outcomes in carers of stroke survivors. As discussed previously, the one study that has been carried out using this model did not look at quality of life. Furthermore, an older version of a reliable and valid means of assessing illness perceptions was used, which did not explore emotional representations. Emotional representations among carers are important to investigate. In addition, carer perceptions of patient and carer perspectives for some of the illness perception dimensions were not investigated.

For future research, it would be important to explore the illness perceptions of carers of stroke survivors using a means of assessing illness perceptions which can examine both cognitive and emotional representations. It might also be pertinent to examine stroke carers' perceptions of both their own perspective and that of the stroke survivor. It

would be valuable to investigate whether the illness perceptions of carers of stroke survivors and their coping account for carer distress and the often neglected area of quality of life. It would be particularly interesting to discover whether their illness perceptions and coping play a greater role in distress and quality of life than demographic, stroke survivor or carer characteristics. Given that the literature suggests that illness perceptions are stronger predictors of outcome than coping, this might be an important area to investigate in this group of carers.

This type of research could further extend our understanding of the application of the SRM in carers. It may provide a greater insight into the processes involved in poor outcomes in stroke carers. This may subsequently enable clinicians to identify those stroke carers who may be more at risk of distress and poor quality of life. If illness perceptions and coping are found to play a significant role in these outcomes, this could facilitate the development of therapeutic interventions. This has the potential to prevent or modify not only poor outcomes in stroke carers but could also indirectly improve the lives of the stroke survivors who they provide support for.

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## **Part 2: Empirical Paper**

### **Using Illness Perceptions and Coping to Understand Distress and Quality of Life in Carers of Stroke Survivors**

## **Abstract**

**Objectives:** To investigate the role of illness perceptions and coping in distress and quality of life in carers of stroke survivors.

**Method:** This was a cross-sectional design using postal questionnaire quantitative data. Seventy-two carers of stroke survivors completed a modified version of the revised Illness Perception Questionnaire, the Brief COPE, the GHQ-12 and the WHOQOL-BREF. Carer, stroke survivor and stroke/illness characteristics were also assessed.

### **Results:**

Illness perceptions accounted for variance in carer distress, psychological quality of life and social relationships, over and above carer, stroke survivor and illness characteristics. Emotional representations and carer beliefs that the stroke has a psychosocial cause were both independently associated with greater distress in carers. The illness perception of greater treatment control was independently associated with better psychological well-being and greater quality of life in social relationships. Coping added significant variance in psychological and social quality of life with less use of passive coping independently predicting better psychological well-being and better social relationships.

**Conclusions:** This study indicated an important role of illness perceptions and coping in distress and aspects of quality of life in carers of stroke survivors. Theoretical and clinical implications and suggestions for further research are discussed.



# **Using Illness Perceptions and Coping to Understand Distress and Quality of Life in Carers of Stroke Survivors**

## **Introduction**

Each year between 174 and 216 people per 100,000 of the population in England and Wales have a first stroke (Mant, Wade & Winner, 2004). Stroke is thought to be the largest single cause of severe disability in the UK (Department of Health, 2001). Many stroke survivors return home from hospital with care and support provided by family members. The tasks which family caregivers may need to carry out require significant resources from the carer and can help stroke survivors to be maintained in the community (Dennis, O'Rourke, Lewis, Sharpe & Warlow, 1998), subsequently easing the demands placed on services. Carers can also play a vital role in the stroke survivor's rehabilitation (Forsberg-Warleby, Moller & Blomstrand, 2001).

It has been estimated that there are 6.8 million adult carers in Britain (Office of National Statistics, 2002). Caring for a family member has been recognised as a stressful experience (Zarit & Edwards, 1999). If caring becomes difficult to manage, this could have negative consequences for the person being cared for in terms of their emotional and physical well-being and could also place increased demands on services. Carers own needs are equally important. Recent national clinical guidelines for stroke

(Intercollegiate Stroke Working Party, 2004) and Government reforms have increasingly recognised carers own needs, beyond their caring role.

Although the impact of stroke on carers has been less researched than the impact on patients (Berg, Palomaki, Lonnqvist, Lehtihalmes & Kaste, 2005; Morrison, 1999), there is agreement that carers of stroke survivors experience certain emotional outcomes. The prevalence of depressive symptomatology among these carers has been found to be between 2½ to 3½ times higher than non-carer national samples of similar age (Schulz, Tompkins & Rau, 1988). Studies have found between that 30-34% of carers are depressed at different points in time after stroke (Anderson, Linto & Stewart-Wynne, 1995; Berg et al., 2005; Schulz et al., 1988), although others report more conservative figures (Dennis et al, 1998). Distress in carers of stroke survivors has been found to be between 42% (Anderson et al., 1995) to 55% (Dennis et al., 1998) and not significantly different to rates of distress in carers of those with dementia (Draper, Poulos, Cole, Poulos & Ehrlich, 1992). Rates of anxiety have been found to be around 37% (Dennis et al., 1998) to 44% (Anderson et al., 1995).

Spouses of stroke patients fare worse than the general population in terms of anxiety, depressed mood, positive well-being, self control and vitality (Forsberg-Warleby et al., 2001). Levels of emotional ill-health in carers 1 year after stroke were found to be 79% and negative effects on family relationships have been commonly reported (Anderson et al., 1995). Estimates of strain among carers and spouses have ranged from 25% to 40% at different points in time after stroke (Blake & Lincoln, 2000; Blake, Lincoln & Clarke, 2003; Bugge, Alexander & Hagen, 1999; Greveson, Gray, French & James, 1991).

There is little consensus concerning the factors that contribute to poor outcomes. It remains difficult to understand which carers are likely to manage and which will experience difficulties (Hodgson, Wood & Langton-Hewer, 1996). Some studies have investigated factors associated with poor outcomes in carers of stroke survivors. Identification of these factors may enable us to develop and target interventions, which could benefit the carer, stroke survivor and potentially ease the burden on services. Some factors that have been identified as possible determinants of poor emotional outcomes in carers have included characteristics of the carer, stroke survivor and of the stroke/illness (see literature review, this volume, for a detailed overview).

The characteristics of the carer that have been linked to poor emotional outcomes in carers of stroke survivors have been the gender of the carer (Forsberg-Warleby et al., 2001); older spousal age (Forsberg-Warleby et al., 2001); being married to the stroke survivor (Schulz et al., 1988; Tompkins, Schulz & Rau, 1988); carer mood or depressive symptoms (Berg et al., 2005; Blake & Lincoln, 2000; Tompkins et al., 1988) and carer physical health (Hodgson et al., 1996). The stroke survivor characteristics that have been linked to poor outcomes in these carers/spouses include older age of the stroke survivor (Berg et al., 2005); younger age of the stroke survivor (Tompkins et al., 1988); stroke severity (Berg et al., 2005); greater physical or functional disability (Blake & Lincoln 2000; Blake et al., 2003; Purk & Richardson, 1994; Thompson, Blundek & Sobolew-Shubin, 1990); aphasia (Kinsella & Duffy, 1979); difficulties with cognitive function (Dennis et al., 1998); behavioural difficulties (Draper et al., 1992) and emotional difficulties in the stroke survivor (Draper et al., 1992; Purk & Richardson, 1994; Wade, Legh-Smith & Langton-Hewer, 1986).

There are aspects of the stroke/illness that have been found to be related to poor emotional outcomes in carers of stroke survivors. These have included a greater time since stroke (Kinsella & Duffy, 1979); stroke survivors having had more than one stroke (Thompson et al., 1990) and less time spent with the stroke patient and more time helping them (Bugge et al., 1999).

Other factors have been identified as important variables in carer outcomes. Fewer social networks before the person's stroke have been identified as a factor related to depression in carers (Tompkins et al., 1988). Blake & Lincoln (2000) noted that strained carers perceived themselves as having less emotional and practical support than those who were not strained. Carers' appraisal of caregiving stress was found to be a predictor of later carer psychological well being (Hodgson et al., 1996). Greater use of non-confronting coping, in the form of indirect coping strategies or avoidance, was found to be associated with higher levels of stress and depression in carers of stroke survivors and older confused people (Matson, 1994). Carers rated as showing better quality of coping were found to have lower levels of stress and depression (Matson, 1994).

There have been numerous studies attempting to identify the determinants of poor emotional outcomes in carers of stroke survivors. Many determinants (e.g. functional disability) show inconsistent findings between studies. Some of these studies suffer from methodological weaknesses such as small sample sizes, biases in sampling, non-standardised and psychometrically weak measures and statistical analyses using correlation only. These and other methodological weaknesses may explain some of the variability in the findings reported. Furthermore, longitudinal studies have shown that

certain variables associated with depression in carers vary with time (e.g. Schulz et al., 1988; Wade et al., 1986). This suggests that, at different stages of the stroke survivors' recovery, some factors are more pertinent than others in accounting for carer outcomes.

Most of the research has focused on psychological outcomes in carers of stroke patients (Low, Payne & Roderick, 1999), leaving other aspects of quality of life neglected, including physical functioning, social relationships and the individual's environment. These areas need further investigation. Additionally, there has been little focus on carer's perceptions of the stroke patient's illness or on the effects that such perceptions may have on carer outcomes. However, one study reported that carer's perception of the recovery of the stroke survivor was related to carer depression during the first year post stroke but not at 2 years post-stroke (Wade et al., 1986). The contribution of social cognitions has been neglected yet these may serve an important role. For example, they may function as direct determinants of outcomes, or may represent mediators, which could potentially explain some of the inconsistent findings in the studies described. Furthermore, social cognition variables may be more modifiable than other factors (e.g. severity of the stroke, type of relationship) and therefore could offer promising avenues for intervention.

While there is increased awareness of some factors contributing to outcomes in carers of stroke survivors, we have little knowledge of the mechanisms by which these factors may be involved. Understanding the processes by which some people do well while others fare more poorly may enable the development of useful psychological interventions.

One model that may offer a framework for understanding outcomes in carers of stroke survivors is Leventhal's self-regulation model (SRM) (Leventhal et al., 1997; Leventhal, Brissette & Leventhal, 2003; Leventhal, Meyer & Nerenz, 1980). The model suggests that individuals construct cognitive and emotional representations of their illness, based on their interpretations of key sources of stimuli (e.g. information provided by external sources or through their own experiences of illness) and in response to health threats.

The SRM proposes the existence of five dimensions of cognitive illness representations, also known as illness perceptions, around which individuals cluster their beliefs. These are *identity* (ideas about the label and associated symptoms of the condition) *timeline* (perceived course or duration of the condition), *cause* (beliefs about the reason for onset or cause of the condition), *consequences* (beliefs concerning the expected outcome or implications of the condition) and *control/cure* (beliefs about the extent to which the condition is controllable or curable). Evidence has been provided for the existence of these dimensions (e.g. Hagger & Orbell, 2003). These illness perceptions guide coping and adaptive outcomes (e.g. in terms of disease state, adherence or psychological well-being). The illness perceptions may also lead to outcomes without coping as a mediator. The coping strategies and outcomes are appraised by the individual, which may lead to modifications of the incoming stimuli, the illness perceptions and the choice of coping strategy.

Emotional illness representations, which exist in parallel and interact with cognitive illness perceptions, guide coping strategies to deal with the emotional reactions, which lead to outcomes and appraisal of coping. The SRM is dynamic and coping and illness

perceptions change through the feedback process of appraisal. However, one criticism is that, while emotional representations may be important determinants of emotional outcomes and other outcomes, much of the current literature has not examined this component of the model, leaving this part of the SRM less well developed.

Many studies have applied Leventhal's SRM in their investigations of illness perceptions in patients with chronic conditions including multiple sclerosis (Jopson & Moss-Morris, 2003), rheumatic disease (Pimm & Weinman, 1998), cardiovascular disorders (Petrie, Weinman, Sharpe & Buckley, 1996), epilepsy (Kemp, Morley & Anderson, 1999), Huntington's disease (Helder et al., 2002) and chronic fatigue syndrome (Heijmans, 1998). Many of these studies have found important direct relationships between illness perceptions and patient outcomes (e.g. Jopson & Moss-Morris, 2003) and some have found that coping has acted as a mediator between illness perceptions and outcomes (e.g. Rutter & Rutter, 2002). In some studies (e.g. Heijmans, 1998), illness perceptions have been found to play a stronger role than coping in patient outcomes. Predictable relationships between cognitive illness perceptions and coping and also between cognitive illness perceptions and outcomes have been found across studies of patients with a range of chronic illnesses (Hagger & Orbell, 2003).

Much of the research investigating illness perceptions has been stimulated by the development of the illness perception questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996) which has provided a standardised way of assessing illness perceptions. A revised version of the illness perception questionnaire (IPQ-R) (Moss-

Morris et al., 2002) incorporates important components derived from the SRM that were overlooked in the original version, including emotional representations.

A growing body of literature is turning attention towards illness perceptions in carers or family members of patients with different conditions. Much of this research has found relationships between family/carer illness perceptions and patient outcomes (e.g. Heijmans, de Ridder & Bensing, 1999; Weinman, Petrie, Sharpe & Walker, 2000). With respect to research examining the influence of carers' illness perceptions on outcomes in carers, Barrowclough, Lobban, Hatton & Quinn (2001) investigated illness perceptions of carers of patients with schizophrenia using a modified version of the IPQ. The authors looked at the control/cure and consequences dimensions from the perspectives of both the carer and patient (e.g. 'their illness has major consequences on my life' and 'their illness has major consequences on their life'). Among other findings, they reported that carer perceptions of greater perceived negative consequences for the patient was related to greater carer distress. Also, greater perceived negative consequences for the carer were related to adverse outcomes in carers, including distress, depression and subjective burden. Carer perceptions of a stronger illness identity (more symptoms reported) were related to greater levels of carer depression. They also found that carer perceptions influenced aspects of patient functioning.

Roberts & Connell (2000) examined illness perceptions in relatives of people with Alzheimer's disease. They found that some relatives had misconceptions which might potentially lead to adverse outcomes. For example, 19% of relatives thought that



significant memory loss was a part of normal ageing and subsequently these individuals might not pursue a medical opinion if experiencing such difficulties themselves.

Only one study (McClenahan & Weinman, 1998) appears to have looked at illness perceptions in carers of stroke survivors. This study explored determinants of carer distress in non-acute stroke, examining illness perceptions and coping as possible independent variables. Other variables examined were demographic factors, characteristics of the stroke survivor (e.g. functional disability, cognitive functioning) and characteristics of the carer (e.g. self-efficacy, social support). Through multiple regression analyses, the authors found that the illness perception of timeline, generalised self efficacy and two coping strategies (venting and suppression) explained a large amount of the variance of carer distress. Those who perceived the timeline to be longer had greater levels of distress and those who suppressed competing activities or focused on and vented their emotions were also more distressed.

In line with other research, this study did not examine other outcomes in carers, such as quality of life. Furthermore, this study was conducted before the publication of the IPQ-R, which has additional components and stronger psychometric properties. In addition, McClenahan & Weinman (1998) did not appear to use the two parallel versions of any of the illness perception dimensions that Barrowclough et al. (2001) had used in their study. It might, for example, be useful to have a greater understanding of not only the carers' perception of the consequences for the stroke survivor but also for themselves.

The aims of the current study are to use the framework of the SRM to investigate illness perceptions and coping in carers of stroke survivors and to understand their relationship to distress and quality of life. It will also be of interest to explore some of the illness perception dimensions from the perspective of the carer and patient as carried out in Barrowclough et al.'s (2001) study. It would be particularly interesting to discover whether stroke carers' illness perceptions and coping play a role in understanding distress and quality of life in addition to the characteristics of the carer, stroke survivor or stroke/illness that previous research has investigated. This type of research could provide a greater understanding of the processes involved in poor outcomes in stroke carers. Although this research is exploratory, it may have implications for the development of therapeutic interventions. This has the potential to prevent or modify poor outcomes in carers.

In summary, there are two principal aims of the current research. The first is to explore the variables that predict carer distress and quality of life, including characteristics of the carer, stroke survivor and stroke/illness, illness perceptions and coping. The second aim is to explore whether illness perceptions and coping predict carer distress and quality of life over and above characteristics of the carer, stroke survivor and stroke/illness.

## **Method**

### **Participants**

The participants were 72 adult individuals identified by adult stroke survivors as the person they considered to be most involved in providing them with support/care. The stroke survivors contacted were known to the Community Stroke Coordinator, based at a Community Neurological Rehabilitation Service in a South England Primary Care Trust (PCT). All individuals, living within this PCT who have had a stroke, are referred to the Stroke Coordinator. This usually consists of individuals discharged from hospital or referred by their General Practitioner (GP).

Except for the following exclusion criteria, all patients that had a stroke and were referred to the Stroke Coordinator from July 2002 to January 2005 were approached to ask whether their carer would like to take part in the study. Exclusion criteria were:

- a. Patients who had not had a stroke
- b. Patients who were in nursing homes
- c. Patients (or their main carer) known to be currently in hospital whom it might be ethically inappropriate to contact.
- d. Patients (or their main carer) who had severe current mental health difficulties whom it might be ethically inappropriate to contact.
- e. Patients who were known not to have a carer.

- f. Patients of carers who could not understand English (as they needed to understand written correspondence, information sheets, consent forms and measures only available in English).

Of 198 stroke survivors contacted, 98 (49.5%) passed on the information sheet to their carer. Of these 98 carers, 16 (16.3%) returned the consent form declining participation in the study. The remaining 82 (83.7%) carers consented to participate and 72 of these returned completed questionnaires. (Full details can be found in Appendix I). A power calculation indicated that a sample size of 98 was required in order to have 80% power at alpha 0.05 and therefore the achieved sample fell short of the desired number (refer to Appendix II for full details). Characteristics of the sample are described in the results section.

### **Ethics**

Ethical approval for this study was obtained from the Mid and South Buckinghamshire Local Research Ethics Committee and approval from the Vale of Aylesbury Primary Care Trust Research and Development Steering Group was also granted (Appendix III).

### **Procedure**

User involvement took place within the service prior to ethical approval to determine whether the questionnaires were acceptable for participants to complete. Two carers completed initial questionnaires. A follow-up telephone call was made to obtain users comments which helped to identify any problems. Some modifications were made and

one measure was omitted as it was deemed to place too much additional burden on participants.

All patients in the Community Stroke Coordinator's database (except those meeting the exclusion criteria), referred from July 2002 to January 2005, were contacted by letter (Appendix IV) inviting their relative/carer to participate in the study. The letter explained the study and asked stroke survivors to pass on an information sheet and consent form to the person they identified to be most involved in providing support/care. They were told that this could be a relative, partner or friend but not a paid or professional carer and must be an adult (aged 18 or over). If they could not identify such a person or did not wish to pass on the letter, they were asked to return the enclosed slip informing us of this, ensuring that we did not contact them again.

The information sheet (Appendix V) invited their relative/carer to take part in the study. Whether they decided to participate or not, carers were asked to read and sign the consent form as appropriate (Appendix VI). Therefore, if they did not give consent, the researcher would not contact either the stroke survivor or their relative/carer again. The patient's GP was informed about the study (Appendix VII). Non-responders (patients who had not returned a reply slip or where the relative/carer had not returned the consent form) were sent a reminder letter (Appendix VIII) after 4 weeks. If after a further 4 weeks there was still no response a second reminder letter was sent to the patient.

Carers consenting to participate in the study were asked to provide contact details on the consent form. Those who ticked a box on the consent form to say they had participated

in other research in the past 6 months were contacted by telephone. This was to ensure that taking part in the study was not going to add excessive burden. All consenting carers were sent the questionnaires by the researcher. Questionnaires were sent out between December 2004 and April 2005. A covering letter (Appendix IX) was sent with the questionnaires. If questionnaires were not returned within 4 weeks, a reminder letter was sent to the carer (Appendix X). Where possible, follow up telephone calls were made to those who had returned questionnaires with missing data.

## **Design**

The study was a within groups cross-sectional design using postal questionnaire quantitative data. The independent variables were carers' illness perceptions, carers' coping and characteristics of the carer, stroke survivor and stroke/illness. The dependent variables were carers' distress and quality of life.

## **Measures**

To ensure consistency of responses, a focused period of four weeks was used in the wording of most questionnaires. All questionnaires were for carers to complete (Appendix XI). Some were about the stroke survivor and some were about the carer.

### *Demographic and Characteristics of the Carer, Stroke Survivor and Stroke/Illness*

Specific questions were devised to obtain demographic data of the patient and carer, including their age, sex, ethnicity and occupation. Some of this information was included in another measure used in this study (WHOQOL-BREF; The WHOQOL Group, 1998) and was therefore not repeated. Other information obtained included,

where the stroke survivor was living; their type of relationship with the stroke survivor (and if spouse/partner, the length of the relationship); type of care provided; amount of time spent caring and whether the stroke survivor had a care package (and if so, how much). Carers were also asked about the number of strokes, time since stroke (first and most recent); whether the stroke survivor has Transient Ischaemic Attacks and lateralisation of weakness/paralysis.

The carer was asked whether the stroke survivor had contacted their GP or other health professional for anxiety, depression or other psychological difficulties before and since their stroke. The same format of questions was also used to obtain an idea of the psychological status of the carer. Carers were also asked whether they had visited their GP or other health professional for any major health problems since their relative's stroke. Participants were asked to provide details if they provided 'yes' responses to any of these questions.

#### *Other Stroke Survivor Characteristics:*

##### *Barthel Index (Mahoney & Barthel, 1965)*

The Barthel Activities of Daily Living Index is a 10 item instrument designed to measure patient function in terms of basic activities of daily living (e.g. bowel and bladder control, feeding and dressing). It is based on actual rather than potential function and was designed for use in individuals with neurological conditions, including stroke. It has been widely used in stroke carer research and completed by carers of stroke survivors. Following the scoring system recommended by Wade (1992), each of the functional categories is either scored from 0-1, 0-2 or 0-3. The total score ranges

from 0-20 with a greater score indicating a greater level of independence. The Barthel Index has good internal consistency, concurrent validity and predictive validity (Wade & Langton-Hewer, 1987). As accompanying guidance notes were deemed unsuitable and too onerous for carers, instructions for completing the measure, closely based on the guidance notes, were constructed.

*Nottingham Extended Activities of Daily Living Index (EADL) (Nouri & Lincoln, 1987)*

As the Barthel Index can be insensitive in community samples the Extended Activities of Daily Living Scale (EADL) was also used. This assesses the level of independence in instrumental activities of daily living and although appearing more sensitive than the Barthel Index, it can be prone to floor effects. Therefore, both the Barthel Index and EADL were used. The EADL consists of 22 activities across four areas; mobility, kitchen, domestic and leisure tasks. Responses are based on whether the person has actually done the activity (e.g. managed to make themselves a hot drink) with four possible responses ranging from 'not at all' to 'alone easily'. It is scored in binary format (0,0,1,1) with a higher score indicating more independence. The EADL has been used in studies of stroke carer research using postal questionnaire methodology (e.g. Blake & Lincoln, 2000). Instructions for the EADL were slightly adapted so that it was from the carer's perspective.

*The Speech Questionnaire (Lincoln, 1982)*

The Speech Questionnaire was used to assess language difficulties in the stroke survivor. It was designed for use with aphasic patients to assess the level of communicative disability (speech and understanding) and can be completed by relatives/carers. It



consists of 14 questions about speech and five about understanding with four categories of response according to the frequency of the behaviour ranging from 'often' to 'never'. Likert scoring was used (0 = never to 3 = always). This is reversed for item 14. A separate score for each of the two scales (speech and understanding) is derived, with a lower score indicating a greater level of difficulty. The speech questionnaire has been reported to have good inter-rater reliability and adequate test retest reliability (Lincoln, 1982). With permission from the author, the category 'often' was modified to 'always/often', following comments made by carers in the pilot study.

*The Rayners Hedge Scales of Functional Independence IV (RHSFI-IV) (Tyerman, 1997)*

The cognitive function subscale from the Rayners Hedge Scales of Functional Independence IV (RHSFI-IV: Cognitive Scale) was designed for use in neurological rehabilitation to assess functional independence. The cognitive subscale can provide a broad estimate of the stroke survivor's level of cognitive independence. The original version of the RHSFI was reported to have good internal reliability and inter-rater reliability. Revised versions have been used in clinical settings with individuals with head injury and in research involving those with stroke, head injury and multiple sclerosis. The latest version, used in this study, consists of 10 items (e.g. orientation, memory function and planning/problem solving). Scoring ranges from 0-10 for each item with scores in increments of two. Each score is assigned a label (e.g. 0 = incomplete incapacity and 10 = independent and normal function). The total score may range from 0-100 with a greater score indicating greater functional independence. With appropriate adaptation, the measure is suitable for completion by relatives/carers.

Permission from the author was given to add instructions and modify the layout to make it easier for carers to complete.

*Other measures:*

*The Revised Illness Perceptions Questionnaire (IPQ-R) (modified) (Moss-Morris et al., 2002)*

A modified version of the Revised Illness Perceptions Questionnaire (IPQ-R) was used to assess the illness perceptions of carers of stroke survivors. The IPQ-R was derived from the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996), developed to provide a quantitative means of assessing the five cognitive illness perceptions of the SRM. It has been used to assess illness perceptions across a range of chronic illnesses in patients and has been adapted for use with partners/carers of patients, including carers of stroke survivors. The additional dimensions included in the IPQ-R are cyclical-timeline perceptions, illness coherence and emotional representations. Additionally, cure/control is now split into treatment control and personal control dimensions. The IPQ-R is reported to have good internal reliability of the subscales, short (3 week) and longer term (6 months) retest reliability and also sound discriminant, known group and predictive validity (Moss-Morris et al., 2002).

Amendments were made with permission and in consultation with one of the principal authors of the measure to ensure its suitability. For the identity scale, the wording of the instructions and items were changed from 'your illness' to 'my relative's stroke'. This scale consists of 14 items but eight items, considered to be common to stroke, were

added. Respondents indicate which symptoms their relative has experienced and which of these they attribute to their stroke, the sum of the latter forming the identity score.

The second part of the measure consists of statements rated on a 5-point likert scale according to how much the participant agrees with the statement (0 = strongly disagree to 5 = strongly agree). This provides scores for the timeline, timeline cyclical, consequences, personal control, treatment control, illness coherence and emotional representation dimensions. Higher scores indicate perceptions of a more chronic timeline, more cyclical timeline, greater personal control, greater treatment control, increased coherent understanding of the condition and more emotional representations. For instructions and items in this section, the term 'stroke health condition' replaced 'your/my illness'. Stroke health condition was defined as referring to the symptoms, effects and underlying medical condition/s associated with their relative's stroke. Using the term 'my relative's stroke' may have been interpreted by carers as referring only to the acute onset event.

A further modification was made enabling carer's perceptions of both stroke survivor and carer perspectives to be examined. Two versions of four of the dimensions were formed including, consequences, personal control, illness coherence and emotional representation dimensions (e.g. 'my relative's stroke health condition has major consequences on their life' and 'my relative's stroke health condition has major consequences on my life'). It was not deemed appropriate to create two versions for the remaining dimensions.

The final section of the modified IPQ-R consisted of the causal items, which contains a list of 18 possible causes. Carers rate these on the same 5-point likert scale according to how much they agree these were causes of their relative's condition. A greater score indicates greater agreement. As described earlier, the term 'stroke health condition' was used.

#### *Brief COPE (Carver, 1997)*

The Brief COPE assesses coping without adding too much burden to participants. It was derived from the COPE inventory, a 60 item instrument which enquires about the extent to which the individual uses that particular coping strategy (Carver, Scheier & Weintrub, 1989). The COPE has been used extensively in carer research. The Brief COPE omits two scales from the COPE, reduces the others to two items and adds one scale. It consists of 28 items, measuring 14 conceptually separate scales (e.g. active coping, using emotional support and venting), each with two items. Responses are scored from 0 (I haven't been doing this at all) to 3 (I've been doing this a lot). Internal consistency was reported as being good, based on an exploratory factor analysis and reliability analysis (Carver, 1997). The introductory wording was modified slightly so that it was applicable to assess the coping of carers of stroke survivors.

#### *The General Health Questionnaire 12 item version (GHQ-12) (Goldberg, 1992)*

The GHQ-12 is designed to detect psychological distress in community settings and was used to assess carer distress. It consists of 12 items, asking whether a particular symptom or behaviour has been recently experienced. There are four responses, varying according to items, which are scored on a 0-3 likert scale. Higher scores indicate greater

levels of distress. The GHQ-12 has been shown to have good internal consistency, test-retest reliability, split-half reliability and produced satisfactory sensitivity and specificity figures. It has been used in stroke carer research (e.g. Blake & Lincoln, 2000; McClenahan & Weinman, 1998).

*WHOQOL-BREF (The WHOQOL Group, 1998)*

The WHOQOL-BREF, which has been used in a range of populations, was used to assess quality of life in carers of stroke survivors. It is a 26 item version of the WHOQOL-100 and is useful when trying to minimise response burden. It consists of four domains: physical, psychological, social and environment. Responses are scored on a 1-5 likert scale based on 'how much', 'how completely', 'how good or satisfied' or 'how often' the participant felt in the last two weeks. Permission has been given from the first author to modify the time span of the questionnaire from the last 'two weeks' to the last 'four weeks' to ensure consistency with other measures in this study. As there are unequal numbers of items for each domain, scores are transformed onto a scale from 0-100 allowing comparisons between domains. Higher scores indicate better quality of life. There is no total score derived from the measure. The WHOQOL-BREF has been reported to have good to excellent psychometric properties of reliability and performs well in preliminary tests of validity (Skevington, Lofty & O'Connell, 2004).

## Results

### Descriptives

#### *Characteristics of the Carers & Stroke Survivors*

Some of the key characteristics of the carers and stroke survivors are shown in table 1.

Table 1: Key characteristics of the carers and stroke survivors

	Characteristics of the Carer	Characteristics of the Stroke Survivor
<b>Gender:</b>		
Male	22 (30.6%)	36 (50%)
Female	50 (69.4%)	36 (50%)
<b>Age</b>		
Mean (standard deviation)	63.76 (14.89)	73.97 (10.97)
<b>Ethnic Group</b>		
White	71 (98.6%)	71 (98.6%)
Black	1 (1.4%)	1 (1.4%)
<b>Occupational Status</b>		
Working full time	14 (19.4%)	0 (0%)
Working part time	9 (12.5%)	2 (2.8%)
Retired	43 (59.7%)	62 (86.1%)
Other	6 (8.3%)	8 (11.1%)
<b>Marital Status</b>		
Married/Living as married	65 (90.3%)	Data not collected
Single or Divorced	7 (9.7%)	Data not collected
<b>Contacting Health professional for psychological difficulties before stroke</b>	9 (12.5%)	9 (12.5%)
<b>Contacting Health professional for psychological difficulties since stroke</b>	7 (9.7%)	14 (19.4%)
<b>Contacting Health professional for health problem since stroke</b>	24 (33.3%)	Data not collected

Most carers (68.1%) were the spouse/partner of the stroke survivor. Their mean length of relationship was 43.45 years (sd 15.89). The remaining 23 (31.9%) carers said that the stroke survivor was their mother/father (26.4%), son/daughter (1.4%), brother/sister (1.4%) or other relationship (2.8%). The mean length of relationship for all carers was 44.79 years (sd 14.48). According to carers' responses, the majority (80.6%) of stroke survivors were reported to be living at home with the participant. Two (2.8%) were living at home with another relative, 10 (14.1%) were living at home alone and two (2.8%) were described as other.

#### *Characteristics of the Illness/Stroke*

Most of the sample (72.9%) said that the person they were caring for had experienced one stroke and the remaining 27.1% reported they had experienced two or more strokes. Carers reported that 20 (27.8%) stroke survivors had their most recent stroke less than 6 months ago, 22 (30.6%) between 6-12 months ago, 21 (29.2%) between 1-2 years ago and nine (12.5%) more than 2 years ago. Twenty-six (36.6%) carers provided 0-19 hours care per week, nine (12.7%) provided 20-34 hours, four (5.6%) provided 35-49 hours, 10 (14.1%) provided 50-99 hours and 15 (21.1%) provided 100 or more hours per week. Seven (9.9%) ticked 'other' but gave responses indicating they were in the caring role most of the time (e.g. '24 hours a day', 'all the time'). Therefore these were categorised as 100 or more hours per week in further analyses. Due to space constraints (and as not forming part of the analysis), some details of the stroke/illness can be found in Appendix XII.

Due to the potentially large number of variables entered for analysis, it was necessary to reduce some of these. With respect to the characteristics of the carers, stroke survivors and stroke/illness, key demographics and the factors that have been identified in the literature to be important in carer outcomes are retained for analysis. This includes:

- Age and Gender of the stroke survivor and carer
- Time since most recent stroke
- Time spent caring
- Type of relationship with the stroke survivor
- Whether the carer visited a health professional for psychological difficulties before their relative's stroke
- Whether the stroke survivor had visited a health professional for psychological difficulties before and also after their stroke.

#### *Data Transformations*

Normality of the measures was tested by examining z scores derived from skewness and kurtosis statistics. A significance value for non-normality was chosen at  $p < .01$  because parametric tests are robust to smaller deviations from normality. Five variables were negatively skewed (Barthel Index, the Speech and Understanding scales from the Speech Questionnaire and the Physical and Social dimensions from the WHOQOL-BREF). Square root transformations were carried out and all the transformed data was subsequently normally distributed with no outliers. Outliers were identified on the basis of having z scores  $\pm 3$ . Only the GHQ-12 had one outlier. This was dealt with by



replacing the figure with a less extreme score but one figure higher than other scores for that variable (Tabachnick & Fidell, 2001).

### *Measures of Stroke Survivor Characteristics*

The means, standard deviations and Cronbach alphas for the measures concerning patient characteristics are shown in table 2.

Table 2: Means, standard deviations and Cronbach alphas for measures concerning patient characteristics

<b>Name of Measure and dimension (number of items per scale)</b>	<b>Mean (standard deviation)</b>	<b>Cronbach Alpha</b>
Barthel Index (10)*	15.14 (4.84)	.89
EADL (22)	9.47 (6.49)	.93
Speech Questionnaire: Speech Scale (14)*	36.63 (5.06)	.84
Speech Questionnaire: Understanding (5)*	12.75 (2.38)	.81
RHSFI-IV: Cognitive (10)	69.97 (25.91)	.95

\* As transformations do not provide meaningful descriptive data, the figures cited here are prior to transformation and are for descriptive purposes only.

### *Illness Perceptions of Stroke Carers*

The means, standard deviations and Cronbach alpha figures for the illness perception dimensions are shown in table 3. There were strong positive correlations between the carer and patient versions of the consequences ( $r = .914, p < .001$ ), personal control ( $r = .810, p < .001$ ), illness coherence ( $r = .704, p < .001$ ) and emotional representation ( $r = .764, p < .001$ ) dimensions. These dyads were therefore combined to produce single

variables of each and these were used in further analyses rather than the separate versions. These are also shown in table 3.

Table 3: Means, standard deviations and Cronbach alpha scores of the IPQ-R (modified) in carers of stroke survivors

<b>IPQ-R Modified Subscale (number of items per subscale)</b>	<b>Mean 1-5 scale (standard deviation)</b>	<b>Cronbach Alpha</b>
Identity (22)	7.15 (4.02)**	.84
Timeline (acute/chronic) (6)	3.59 (.95)	.91
Timeline cyclical (4)	2.47 (.92)	.91
Consequences-Patient (6)*	3.51 (.81)	.87
Consequences-Carer (6)*	3.37 (.81)	.85
Consequences Combined (12)	3.44 (.79)	.93
Personal Control-Patient (6)*	3.16 (.80)	.85
Personal Control-Carer (6)*	3.10 (.71)	.76
Personal Control Combined (12)	3.12 (.72)	.90
Treatment Control (5)	3.31 (.78)	.81
Illness Coherence-Patient (5)*	3.40 (.92)	.88
Illness Coherence-Carer (5)*	3.68 (.87)	.89
Illness Coherence Combined (10)	3.54 (.83)	.92
Emotional Representations-Patient (6)*	3.31 (.83)	.85
Emotional Representations-Carer (6)*	3.22 (.82)	.84
Emotional Representations Combined (12)	3.27 (.78)	.91

\* These items are presented purely for descriptive purposes and are not included in further analyses as explained earlier.

\*\* Range for identity = 0-22.

For the purposes of analyses and data reduction the 18 cause items from the IPQ-R (modified) were analysed by means of a principal components analysis with varimax rotation. Three meaningful components were derived using Catell's scree test with all items having factor loadings above 0.4. These components are labelled psychosocial cause (their emotional state, family problems, stress, own behaviour, mental attitude and personality), internal/self biological cause (smoking, alcohol, hereditary, diet) and external biological cause (pollution, altered immunity, poor medical care in past, chance/bad luck and germ/virus). Reliability analysis of each component indicated a Cronbach alpha value of .83, .74 and .60 respectively. Three items (overwork, accident/injury and ageing) did not load onto any of the components and were therefore deemed uninterpretable. A subsequent check of normality of the new components revealed that the internal/self biological cause component was positively skewed. A square root transformation was carried out and data was subsequently normally distributed.

### *Coping Behaviours of Carers*

For data reduction purposes, a principal components analysis with varimax rotation was carried out on the Brief COPE. One subscale (denial) had a Cronbach alpha value of .42 and was not included in the principal components analysis. Outliers were dealt with in the way described earlier before the principal components analysis was carried out. Two meaningful components were derived using Catell's scree test with all items having factor loadings above 0.4. These components are labelled active coping (planning, active coping, using instrumental support, using emotional support, positive reframing, religion, acceptance and humour) and passive coping (substance use, behavioural

disengagement, venting, self-distraction and self-blame) with Cronbach alpha values of .83 and .63 respectively. A subsequent check of normality of the new components revealed that passive coping was positively skewed. A square root transformation was carried out and data was subsequently normally distributed.

### *Distress and Quality of Life of Carers of Stroke Survivors*

Using a cut-off score of 3 to indicate caseness (Goldberg & Williams, 1988), which requires scoring using the binary format (0,0,1,1), 61.1% of the carers in the sample were distressed. Table 4 shows the means, standard deviations and Cronbach alpha values for distress and the four dimensions of quality of life.

Table 4: Means, standard deviations and Cronbach alphas for distress and quality of life in carers of stroke survivors

Outcome Measure (number of items per scale)	Mean (standard deviation)	Cronbach Alpha
<b>GHQ-12</b> (using likert scoring)	12.90 (4.36)	.81
<b>WHOQOL-BREF</b>		
Physical (7)*	71.68 (18.04)	.87
Psychological (6)	66.56 (14.32)	.78
Social (3)*	64.35 (20.65)	.71
Environmental (8)	70.53 (12.43)	.74

\* As transformations do not provide meaningful descriptive data, the figures cited here are prior to transformation and are for descriptive purposes only.

### **Univariate Correlations**

The univariate correlations between the illness representation and coping variables are shown in table 5.

Table 5: Correlations between the illness perceptions and coping variables in the final analysis: Pearsons r

(N=72 except where stated)		Identity	Timeline	Timeline Cyclical	Consequences	Treatment Control	Personal control	Illness Coherence	Emotional Reps	Psychosocial cause	Internal/Self Biological Cause	External Biological Cause	Active Coping	Passive Coping
		Identity												
		Timeline (acute/chronic)	.206											
		Timeline Cyclical	.080	-.013										
		Consequences (patient & carer)	<b>.480***</b>	<b>.614***</b>	<b>.282*</b>									
		Treatment Control (N=71)	-.150	<b>-.515***</b>	.043	<b>-.351**</b>								
		Personal Control (patient & carer)	-.094	<b>-.525***</b>	.029	<b>-.247*</b>	<b>.625***</b>							
		Illness Coherence (patient & carer)	-.222	.188	<b>-.268*</b>	-.102	<b>-.247*</b>							
		Emotional Reps. (patient & carer)	<b>.531***</b>	<b>.322**</b>	<b>.321**</b>	<b>.590***</b>	-.172	<b>-.309**</b>						
		Psychosocial Cause	.159	-.055	.230	.139	.103	.173	<b>.236*</b>					
		Internal/Self Biological Cause	<b>.343**</b>	.164	-.078	<b>.240*</b>	.024	.006	.217	.014				
		External Biological Cause	.033	-.085	<b>.233*</b>	.139	.148	.105	.184	.000	-.014			
		Active Coping	<b>.289*</b>	-.067	.198	<b>.245*</b>	.190	.205	<b>.258*</b>	<b>.254*</b>	-.107	.228		
		Passive Coping	<b>.277*</b>	.024	.036	.169	.034	.191	<b>.252*</b>	<b>.244*</b>	.159	-.025	-.056	

\*p<.05. \*\*p<.01. \*\*\*p<.001

There were a number of significant correlations as would be predicted by the SRM. Some of these were moderate to strong (.480 to .614), although none were very strong. The strongest association was between perceptions of greater personal control and greater treatment control. These were both also moderately associated with a more acute timeline. Perceptions of serious consequences were moderately/strongly associated with a strong illness identity (more symptoms) and a chronic timeline. Greater emotional representations were moderately associated with a strong illness identity and perceptions of serious consequences.

In accordance with the aims of the research, univariate correlations were first carried out to examine the relationship between the independent variables and each of the outcome variables. As some of the independent variables did not represent continuous data (e.g. gender), these were dummy coded and point biserial (rpb) correlations were carried out. For all other variables Pearson correlations (r) were employed. Correlations between carer, stroke survivor and stroke/illness characteristics, including patient functioning with distress (GHQ-12) and the four dimensions of quality of life (WHOQOL-BREF) are shown in table 6. Correlations between illness perceptions and coping with distress and quality of life are shown in table 7. Significant correlations are shown in bold.

### *Correlations with Distress*

In terms of relationships with distress, greater distress was significantly associated with shorter time since the most recent stroke; carers report of psychological difficulties in the stroke survivor since their stroke; reduced functional ability of the stroke survivor in extended activities of daily living; greater difficulties with speech and reduced cognitive

Table 6: Correlations between carer, patient and illness characteristics with distress and quality of life

Characteristics of carer, stroke survivor, stroke/illness and functioning (N=72 except where stated)		Pearsons r Correlations with GHQ & WHOQOL-BREF domains			
	GHQ	Physical†	Psychological	Social‡	Environmental
Age of carer	-.160	.216	.176	-.129	.045
Age of stroke survivor	-.044	-.031	.248*	-.059	.059
Gender of carer†	.215	.017	-.243*	.086	.042
Gender of stroke survivor†	-.042	-.140	.139	.039	-.053
Time since most recent stroke	-.238*	-.109	.034	.119	.022
Time spent caring (N = 71)	.122	.178	-.143	.096	.007
Type of relationship with stroke survivor†	.098	-.256*	-.054	.131	-.023
Carer psychological difficulties before stroke†	-.193	.015	.071	-.006	-.190
Stroke survivor psychological difficulties before stroke†	-.008	.054	-.089	.097	-.041
Psychological difficulties in stroke survivor since stroke†	-.286*	-.210	.179	-.102	.124
Barthel Index‡	.226	.092	-.209	.136	-.152
EADL	-.292*	-.190	.207	-.148	.288*
Speech‡	.297*	.255*	-.395**	.142	-.230
Understanding‡	.207	.371**	-.255*	.014	-.169
RHSFI-IV: Cognitive	-.352**	-.166	.311**	-.188	.350**

\*p<.05. \*\*p<.01.

† point biserial correlations. Codes: carer gender 1=male, 2=female; stroke survivor gender 0=male 1=female; relationship with stroke survivor 0=spouse/partner, 1=not spouse/partner; psychological difficulties in carer before stroke, in stroke survivor before stroke and in stroke survivor since stroke 0=yes, 1=no.

‡ these variables were transformed from being negatively skewed. As the variable was reflected correlations are in the reverse direction.

Table 7: Correlations between illness perceptions/coping with distress and quality of life

<b>Illness Perceptions and Coping</b> (N=72 except where stated)	<b>Pearsons r Correlations with GHQ &amp; WHOQOL-BREF domains</b>			
	<b>GHQ</b>	<b>Physical†</b>	<b>Psychological</b>	<b>Social†</b> <b>Environmental</b>
Identity	<b>.402***</b>	.194	<b>-.331**</b>	.080 -1.122
Timeline (acute/chronic)	.166	-.061	<b>-.326**</b>	<b>.323**</b> -1.178
Timeline Cyclical	-.018	-.151	.083	-.219 .188
Consequences (patient and carer)	<b>.351**</b>	.142	<b>-.370**</b>	.189 <b>-.246*</b>
Treatment Control (N=71)	-.165	-.200	<b>.315**</b>	<b>-.317**</b> <b>.253*</b>
Personal Control (patient and carer)	-.036	-.162	.193	-.101 .135
Illness Coherence (patient and carer)	-.160	-.013	-.011	.034 .043
Emotional Representations (patient and carer)	<b>.444***</b>	.094	<b>-.308**</b>	.077 -1.182
Psychosocial Cause	<b>.357**</b>	.096	-.223	.049 -.060
Internal/Self Biological Cause	.153	.065	<b>-.259*</b>	<b>.239*</b> -1.110
External Biological Cause	-.180	-.031	.120	-.113 -.057
Active Coping	<b>.347**</b>	.124	.012	-.221 -1.154
Passive Coping	<b>.284*</b>	.033	<b>-.323**</b>	<b>.360**</b> -1.165

\*p<.05. \*\*p<.01. \*\*\*p<.001

† these variables were transformed from being negatively skewed. As the variable was reflected correlations are in the reverse direction.



functional independence. Greater distress was also significantly associated with a stronger illness identity (more symptoms); greater perceived consequences for the patient and carer; greater emotional representations of the patient and carer; attributions to a psychosocial cause and greater use of both active and passive coping.

### *Correlations with Quality of Life*

In terms of relationships with quality of life, greater physical quality of life was associated with not being a spouse/partner and with less difficulties with speech and understanding. Physical quality of life was not associated with any of the illness perception dimensions or coping.

Greater psychological quality of life was associated with older age of the stroke survivor; being a male carer; fewer difficulties with speech and understanding and greater cognitive functional independence. Greater psychological quality of life was also associated with a weaker illness identity; a perceived shorter timeline; fewer perceived consequences for the patient and carer; greater perceived treatment control; fewer emotional representations of the patient and carer; fewer attributions to an internal/self biological cause and less use of passive coping.

Social quality of life was not associated with any of the carer, patient or stroke/illness characteristics. Greater social quality of life was associated with a perceived shorter timeline; greater perceived treatment control; fewer attributions to an internal/self biological cause and less use of passive coping.

Greater environmental quality of life was associated with greater functional ability of the stroke survivor in activities of daily living and greater cognitive functional independence. Greater environmental quality of life was also associated with fewer perceived consequences for the patient and carer and greater perceived treatment control.

### **Regression Analyses**

A series of stepwise multiple regression analyses were carried out to explore the research aims. As would be predicted by the SRM, there were significant inter-correlations between the illness perception variables. Although there were also relationships between the illness perception and coping variables, these were modest. According to Tabachnick & Fidell (2001) problems of multicollinearity occur when independent variables correlate at .90 or higher and they recommend caution when they correlate at .70 or higher. Given that none of the correlations between and within the illness perception and coping variables exceeded .614, multicollinearity was not considered a problem. Only variables that were significantly correlated to the dependent variables ( $p < .05$ ) were entered into the regression. Characteristics of the carer, patient and illness were entered into the first block and the illness perception and coping variables into the second. Exceptions were when none of the variables in one block correlated with the dependent variable. In all tables significant F or F change and Beta values are shown in bold.

### *Predicting Distress*

The results of the stepwise multiple regression analysis to predict carer distress is presented in table 8. In the first model cognitive independence was significant explaining 11.2% of the variance in distress. The addition of patient psychological difficulties since the stroke led to significant change in Adjusted R square accounting for an additional 4.3% of the variance. The addition of emotional representations led to significant change in Adjusted R square explaining an additional 8.8% of the variance. In the final model, where attribution to a psychosocial cause for the stroke was added, there was significant change in Adjusted R square with an additional 4.2% of variance. In this final model, emotional representations and attributions to a psychosocial cause for the stroke were both independent predictors. The cognitive independence of the stroke survivor and the presence of psychological difficulties in the stroke survivor since the stroke were independent predictors in earlier models but not in the final model.

Table 8: Summary of stepwise multiple regression analysis testing the predictors of distress.

Model	Adjusted R Square	Adjusted R Square Change	F / F Change (df)	Beta model 1	Beta model 2	Beta model 3	Beta model 4
<b>1 RHSFI</b>	<b>.112</b>		<b>9.930 (1, 70)**</b>	<b>-.351**</b>	<b>-.315**</b>	<b>-.242*</b>	<b>-.202</b>
<b>2 Patient psychol difficulties since stroke</b>	<b>.155</b>	<b>.043</b>	<b>4.552 (1, 69)*</b>		<b>-.236*</b>	<b>-.139</b>	<b>-.145</b>
<b>3 Emotional Reps</b>	<b>.243</b>	<b>.088</b>	<b>9.006 (1, 68)**</b>			<b>.336**</b>	<b>.289*</b>
<b>4 Psychosocial Cause</b>	<b>.285</b>	<b>.042</b>	<b>5.032 (1, 67)*</b>				<b>.235*</b>

\*p<.05. \*\*p<.01.

### *Predicting Physical Quality of Life*

The results of the stepwise multiple regression analysis to predict carers' physical quality of life is shown in table 9. The model was significant accounting for 12.6% of the variance in physical quality of life. The patients' communicative understanding, which was the only variable remaining in the regression analysis, was an independent predictor. Neither illness perceptions nor coping significantly correlated with physical quality of life and were therefore not entered into this analysis.

Table 9: Summary of stepwise multiple regression analysis testing the predictors of physical quality of life

Model	Adjusted R Square	F (df)	Beta
1 Understanding	.126	11.202**	.371**

\*\*p<.01.

### *Predicting Psychological Quality of Life*

The results of the stepwise multiple regression analyses to predict carer psychological quality of life are presented in table 10. In the first model, the speech ability of the stroke survivor accounted for 13.5% of the variance in psychological quality of life. The addition of carer gender led to significant change in Adjusted R square accounting for an additional 7.0% of the variance. The addition of the illness perception of treatment control led to significant change in Adjusted R square explaining an additional 5.8% of the variance. In the final model, where passive coping was added, there was significant

change in Adjusted R square with an additional 5.5% of the variance. In this final model, speech ability of the stroke survivor, carer gender, treatment control and passive coping were all independent predictors.

Table 10: Summary of stepwise multiple regression analysis testing the predictors of psychological quality of life

Model	Adjusted R Square	Adjusted R Square Change	F / F Change (df)	Beta model 1	Beta model 2	Beta model 3	Beta model 4
1 Speech	.135		11.905 (1, 69)**	-.384**	-.406***	-.322**	-.295***
2 Gender of carer	.205	.070	7.133 (1, 68)**		-.285**	-.331**	-.289**
3 Treatment Control	.263	.058	6.299 (1, 67)*			.276*	.285***
4 Passive Coping	.318	.055	6.452 (1, 66)*				-.255**

\*p<.05. \*\*p<.01. \*\*\*p<.001

### *Predicting Social Quality of Life*

The results of the stepwise multiple regression analysis to predict quality of life in social relationships is shown in table 11. Characteristics of the carer, patient and illness did not significantly correlate with social quality of life and were therefore not included in this regression analysis. In the first model passive coping was significant explaining 11.5% of the variance in social quality of life. The addition of treatment control in the second model led to significant change in Adjusted R square accounting for an additional 9.9% of the variance. Both passive coping and treatment control were independent predictors in this final model.

Table 11: Summary of stepwise multiple regression analysis testing the predictors of social quality of life

Model	Adjusted R Square	Adjusted R Square Change	F / F Change (df)	Beta model 1	Beta model 2
1 Passive Coping	.115		10.111 (1, 69)**	.358*	.369*
2 Treatment Control	.214	.099	9.672 (1, 68)**		-.330*

\*p<.05. \*\*p<.01.

#### *Predicting Environmental Quality of Life*

The results of the stepwise multiple regression analysis to predict carer environmental quality of life is shown in table 12.

Table 12: Summary of stepwise multiple regression analysis testing the predictors of environmental quality of life

Model	Adjusted R Square	F (df)	Beta
1 RHSFI	.102	8.916 (1, 69)**	.338**

\*\*p<.01.

The model was significant accounting for 10.2% of the variance in environmental quality of life. The cognitive independence of the stroke survivor, which was the only variable remaining in the regression analysis, was an independent predictor. Coping had not been entered into this analysis as it had not significantly correlated with environmental quality of life.

## **Discussion**

There were two principal aims of the current study. The first was to explore the variables that predict distress and quality of life in carers of stroke survivors. The other principal aim was to explore whether illness perceptions and coping predicted distress and quality of life over and above characteristics of the carer, stroke survivor and stroke/illness. The main findings are summarised in terms of these aims and possible interpretations are discussed.

The study indicated that 61.1% of carers were distressed. This figure appears higher than that reported in other studies, where estimates using other versions of the GHQ were also high, ranging from 42% (Anderson et al., 1995) to 55% (Dennis et al., 1998). Individuals in this study represented a community sample of stroke carers, not just carers of stroke survivors that were referred for specific difficulties, yet these carers still have high levels of distress. Interestingly, only 9.7% of carers reported contacting a health professional for psychological difficulties since their relative's stroke. This could suggest that a large proportion of distressed carers are not seeking help.

Although norms are currently unavailable for the WHOQOL-BREF, mean quality of life scores in 'well' and 'sick' (covering physical/mental health problems based on ICD-10 categories) populations have been published (Skevington et al., 2004). When transformed to the same 0-100 scale, physical quality of life in stroke carers appears slightly worse than the well population but slightly better than the sick population, as

might be expected. On the psychological dimension, carers' scores were worse than the well population and minimally worse than the sick population. Carers' scores appeared substantially lower than well and sick populations on the social relationships dimension. Lastly, on the environmental dimension, carers' scores were similar to both populations. When norms become available it will be interesting to see whether differences are significant. It is noteworthy that the two quality of life domains (psychological and social) where illness perceptions and coping explained additional significant variance are the same two domains that seem poorer than both well and sick populations.

### **Predicting Distress**

The results of the regression analysis indicated that there were four key factors that together predicted carer distress and explained a total of 28.5% of the variance. Of the characteristics of the carer, stroke survivor and illness, reduced cognitive independence of the stroke survivor explained 11.2% of the variance in carer distress. Decreased cognitive independence is likely to place greater demands on the carer as they may need to offer more help in terms of orientating the stroke survivor to time, place or person, reminding them to do certain tasks or planning and decision making. This could increase carers' level of distress. Additionally, the experience of caring for someone who previously did not have such difficulties, who is now having problems with day to day tasks because of decline in their cognitive function, is likely to be distressing in itself. However, in the final model cognitive independence did not remain an independent predictor of distress.



The presence of patient psychological difficulties since the stroke added a further 4.3% of the variance in carer distress. Before illness perceptions were included in the model, the presence of patient psychological difficulties since the stroke was an independent predictor of carer distress. This independent association is consistent with findings that have linked emotional difficulties in the stroke survivor with carer/spousal depression (Wade et al., 1986), morale (Purk & Richardson, 1994) and burden and distress (Draper et al., 1992). This could suggest that the stroke survivors' emotional difficulties have a negative impact on carer outcomes, although the converse is possible. However, this independent association was not significant when illness perceptions were included in later models.

With respect to the addition of illness representations and coping over and above the characteristics of the carer, stroke survivor and illness, emotional representations added 8.8% of the variance and this was also an independent predictor of carer distress. The emotional responses generated by the illness were found to increase carer distress.

While it might be proposed that emotional representations are not distinct from emotional distress, it has been shown that the emotional representations subscale of the IPQ-R is not simply a proxy of the individual's mood (Moss-Morris et al. 2002).

Furthermore, the emotional representations scale in this study involved not only the carers' perceptions of their own emotional responses to the stroke but also their perception of the stroke survivors' emotional representations of the stroke. This finding suggests that the emotional processing dimension of the SRM makes an important contribution to our understanding of carer outcomes. How the carer appraises threats

themselves and how they believe the stroke survivor appraises these threats could have a negative impact on carer distress.

Carer beliefs that the stroke had a psychosocial cause added a further 4.2% of the variance and was an independent predictor of distress. There could be several reasons for this. One possibility could be that carers may have issues of responsibility or self-blame, particularly as family problems load onto this dimension. Relatives may feel under greater pressure to alleviate psychosocial stressors as they may, for example, fear that this could lead to a further stroke. Hence, the responsibility of reducing such stressors or failing to have a positive impact on these might lead to greater carer distress. Carers might even be fearful that they themselves are at risk of stroke, especially if they share the same psychosocial stressors. These possibilities require further exploration. Although not investigated in this study, such carer causal beliefs could have a detrimental impact on the stroke survivor, particularly if they involve criticism or blame of the patient (Weinman, Heijmans & Figueiras, 2003).

In contrast to McClenahan and Weinman's (1998) findings, there was no association between carers' perceptions of a chronic timeline and distress. One explanation could be that different versions of the IPQ were used. In the latest version, used in this study, the previously single category of timeline is now split into two dimensions, timeline and cyclical timeline. Hence, there may be subtle differences in the perceptions being measured between the two studies. Additionally, their sample only included carers of stroke survivors who had experienced their stroke at least 11 months prior to the study.

The current study included carers of stroke survivors at an earlier point in time post-stroke and beyond 11 months.

Neither active nor passive coping contributed to the regression model, although both had significant univariate correlations with distress. According to coping theory, active coping is likely to reduce distress and passive coping is likely to increase it. However, in this study, both active and passive coping were positively correlated with distress. One interpretation could be that those who are more distressed are attempting more coping efforts (active and passive). This is consistent with the SRM. However, it is also possible that within the group using active coping, there are a subgroup of people that use active coping and consequently feel less distressed. This may, at least, explain why active coping does not emerge as an independent predictor of distress.

### **Predicting Quality of Life**

Characteristics of the carer, stroke survivor and illness predicted physical, psychological and environmental quality of life but not social quality of life. In terms of their role over and above these characteristics, illness perceptions and also coping predicted psychological and social quality of life adding significant variance. However, neither added variance or predicted physical or environmental quality of life.

The regression analysis indicated that the only carer, stroke survivor and illness characteristic to explain a significant amount of variance (12.6%) and independently predict carers' physical health was the communicative understanding skills of the stroke survivor. Greater physical quality of life was independently predicted by fewer

difficulties in the stroke survivor's communicative understanding skills. This suggests that carers might be at risk of poor health if caring for someone with difficulties in understanding. These individuals might have a greater burden of physical care. For example, stroke survivors who misunderstand instructions may do a task incorrectly, which could create additional tasks for the carer. This might leave the carer less time to manage their own health needs. Carers who may acquire additional tasks could also become increasingly frustrated, which could negatively impact on their physical health, such as their sleep. These possible mechanisms need further investigation. The relationship between understanding and carer physical health seems consistent with research carried out by Kinsella & Duffy (1979). They found that spouses of aphasic stroke survivors had poorer social adjustment than spouses of non-aphasics. However, others (McClenahan & Weinman, 1998) have not found relationships between language difficulties and carer distress. In the current study this relationship has been found in an aspect of quality of life not previously investigated, making comparisons to past research more difficult.

The results of the regression analysis indicated that there were four factors that together predicted carer psychological quality of life and explained a total of 31.8% of the variance. With respect to the characteristics of the carer, stroke survivor and illness that predicted carers' psychological quality of life, fewer difficulties with speech in the stroke survivor explained 13.5% of the variance. This was also an independent predictor in the final model. Various mechanisms could account for this relationship. For example, carers may feel less frustrated about understanding the person they are caring for than carers of those with speech difficulties. Stroke survivors with better speech

abilities may be less frustrated if they are able to make their carer understand them, which may positively influence carer mood. Better speech also gives the stroke survivor opportunities to support the carer. If speech is less affected by stroke, carers could believe that the stroke has not had such a global impact and this may contribute to greater carer psychological quality of life. However, other studies (Forsberg-Warleby et al., 2001) have not found a relationship between spousal psychological well-being and stroke survivor language difficulties. It is possible that dissimilarities between the studies could explain these differences. For example, Forsberg-Warleby et al. (2001) only included spouses in their sample and all were below 75 years. Also, different measures to assess psychological well-being were used.

The addition of carer gender added a further 7.0% of the variance, with an independent association between male carers and better psychological quality of life in the final model. This suggests that females are at greater risk of poor psychological quality of life. While many have not found differences between male and female carers in outcomes, Dennis et al. (1998) found that females reported more anxiety than males. However, they suggest that this could reflect sex differences in the general population. This might be applicable to the findings of the current study. In a large sample of well and sick individuals, significant sex differences in the psychological dimension of the WHOQOL-BREF have been found, with women reporting poorer psychological quality of life than men (Skevington et al., 2004).

With respect to the addition of illness representations and coping over and above the characteristics of the carer, stroke survivor and illness, the illness perception of greater

treatment control added 5.8% of the variance and was an independent predictor of greater psychological quality of life. Greater use of passive coping contributed an additional 5.5% of the variance and was an independent predictor of poor psychological quality of life. Before exploring the meaning of these relationships, it is worthwhile commenting that these two variables were also predictors of social quality of life and together accounted for 21.4% of the variance in this dimension. None of the characteristics of the carer, stroke survivor or illness were related to social quality of life. Greater use of passive coping explained 11.5% of the variance and was an independent predictor of poor social quality of life. Perceptions of a greater treatment control added 9.9% of variance and was an independent predictor of greater social quality of life.

Greater beliefs that treatment may offer more control appears to impact positively on carers' psychological well-being and social relationships. This is consistent with research in patient groups which has found that high perceived control over the illness is associated with psychological well-being and vitality (Hagger & Orbell, 2003).

However, treatment control beliefs might interact with outcomes differently in carers. In the current study it is possible that carers' treatment control beliefs provide them with external sources of control, which benefit their psychological well-being and their relationships with others. This interpretation is similar to that reported by Jopson & Moss-Morris (2003) who found that higher treatment control was associated with less mental fatigue in those with multiple sclerosis. If carers believe that the stroke survivors' treatment is likely to be effective or will control their condition it may engender a greater sense of control and predictability over the situation and they may

feel more supported, which is also likely to enhance their psychological well-being. Positive treatment control beliefs can also provide optimism about the future which could help carers to maintain their psychological well-being and their social relationships.

The other independent predictor of poor psychological and social quality of life was greater use of passive coping. If carers are using strategies such as venting or substance use, they may not be actively seeking a means of solving a particular difficulty or assistance for a problem that might be amenable to change. It has been suggested that this could be associated with an individual's belief that active coping is unlikely to be effective and may represent a form of learned helplessness (Hagger & Orbell, 2003). Hence, this could impact negatively on carers' psychological well-being. Furthermore it may also be possible that those engaging in self-blame as a coping strategy, which was included in the passive coping scale, may be construing difficulties in the caring situation as their fault and criticising themselves. This may adversely affect their psychological well-being. Others have found that passive coping strategies including distraction, venting and substance use are negative predictors of mental health (Vollrath, Alnaes & Torgersen, 2003). It is also feasible that psychological well-being may influence the coping strategies adopted by the individual. If the carer's psychological well-being is poor then it could follow that they are less likely to be able to utilise active coping resources and therefore turn to more passive strategies.

As passive coping was also independently associated with social quality of life it might be proposed that by carers using strategies such as behavioural disengagement or

venting, which might be construed as self-focused, they may not be actively maintaining social relationships. Furthermore, they could be neglecting them and subsequently they may become poorer. Passive coping strategies such as venting have been linked to poor outcomes in stroke carers (McClenahan & Weinman, 1998). The relationship between passive coping and social relationships could be bi-directional. It is possible that carers with poor social relationships rely on passive coping (e.g. venting, self-blame, self-distraction) because they have fewer resources for support. Social resources can strengthen coping efforts through emotional support and this can create more opportunities to build self-confidence and self-esteem (Moos & Holahan, 2003).

The regression analysis indicated that the only carer, stroke survivor and illness characteristic to explain a significant amount of variance (10.2%) and independently predict carers' environmental quality of life was the cognitive independence of the stroke survivor. Greater environmental quality of life was independently predicted by greater cognitive independence of the stroke survivor. It is possible that carers who believe that the stroke survivor has limited cognitive independence may also perceive that their environment is not satisfactory, particularly with respect to meeting the needs of someone who may require a facilitative environment to help them to manage their cognitive difficulties. Furthermore, caring for someone with reduced cognitive independence could limit the carer's opportunities to have access to leisure activities and opportunities for improving their environment and therefore lead them to have poorer environmental quality of life.



While illness perceptions and coping significantly added to the variance in some of the outcomes, neither played an important role in physical or environmental quality of life. Even when illness perceptions or coping explained significant variance in outcomes, there was considerable variance unexplained. This indicates that other factors that might account for carer outcomes, particularly in physical health and environmental quality of life, should be considered. Factors such as personality style, previous psychosocial functioning, genetics, income, intelligence and social support, among other variables, may make contributions to carer outcomes. It would be anticipated that some of these factors might influence certain outcomes more than others.

### **Limitations**

It is important to consider some limitations of this research which should be taken into account (see critical appraisal for a fuller discussion of limitations). The sample size was smaller than desired ( $n = 72$ ). A larger sample size would have increased the power to detect significant relationships. Another issue is that those participating in the study were first selected by the stroke survivors and after decided themselves whether or not to participate. It is possible that those participating in the study, could have been more distressed or had poorer quality of life or conversely might have been the least distressed or had better quality of life. Apart from this possible self-selection bias, an important strength of this study is that the sample targeted were carers of stroke survivors in the community rather than just those referred for specific difficulties. There are limitations concerning how representative the sample might be of the general stroke carer population. For example, the sample mostly consists of carers of those who had a stroke within the last 2 years. As others have found (Schulz et al., 1988; Wade et al., 1986),

the determinants of poor outcomes in carers change over time. Therefore it is not possible to generalise these findings to carers of stroke survivors at later points in their recovery.

Some of the measures to assess certain constructs have unknown psychometric properties. For example, using a single question to ask carers whether stroke survivors had contacted a health professional for psychological difficulties (since their stroke) may not accurately reflect the number of stroke survivors experiencing such problems. As this question reflects only health professional contact there may be individuals who experience difficulties but do not seek help. Additionally, some of the measures may represent carer perceptions of stroke survivors function rather than objective functioning. This is an issue that Blake et al. (2003) highlighted in their research.

It is possible that, by using the Brief COPE, important aspects of coping in stroke carer populations may have been missed. Measures of coping by means of checklists are not always sufficiently specific and can ignore personal characteristics (Hagger & Orbell, 2003). This could explain why coping did not correlate with more outcomes and did not account for more variance. Alternative or additional means of assessing coping might therefore prove useful (e.g. behavioural methodologies).

A vital principle of the SRM is the notion of causal relationships between illness perceptions, coping and outcomes. As this study is cross-sectional, it is not possible to infer the direction of the relationships found. Longitudinal and experimental designs may allow us to test directions of the relationship.

As a relatively large number of independent variables were entered into the correlations, there is an increased risk of a type I error. A more stringent level of significance could have been adopted or Bonferroni's correction could have been applied to control for multiple comparisons. However, the use of Bonferroni's correction has been criticised as this method can lead to inflation of type II errors and important findings are therefore lost (Perneger, 1998). This would further reduce statistical power, which in an already smaller than desired sample size, might result in potentially relevant findings being deemed unimportant. Given the exploratory nature of the study, it was felt that the risks of a type I error outweighed the losses of making a type II error. Efforts were made to reduce the number of variables in the study (see critical appraisal). To further minimise unnecessary multiple testing, the two aims were explored in one single stepwise multiple regression analysis for each outcome variable. Current results should be treated with caution and replication of this study would be important to determine the reliability of the findings.

### **Implications**

There are several theoretical and clinical implications from this research. Firstly, this study emphasises the need to include psychological variables in understanding stroke carer outcomes. Rather than looking solely at characteristics of the carer, patient or illness, we need to adopt a biopsychosocial model, considering a wider range of factors that may influence carer outcomes. More specifically, this study has shown that there is a role for the application of the SRM in stroke carer outcomes. More research is needed to understand the links between illness perceptions, coping and outcomes in carers.

However, illness perceptions and coping alone are not sufficient as there is still much variance in carer outcomes unexplained. Therefore other constructs that might be important, such as social support or carers' appraisals of coping, need to be examined.

The findings support previous research which has found that many carers of stroke survivors are distressed. There are also indications that they experience poorer quality of life, mainly in psychological and social dimensions. This suggests that services need to develop a means of formally assessing the needs of stroke carers, beyond simply their physical needs. Services must pay attention to the wider context of caregiving. Given such high levels of distress, yet comparatively fewer carers contact a health professional for psychological difficulties, services need to access those who are experiencing problems but are not seeking help. One possibility could be to investigate the factors that might drive help seeking in carers or conversely the factors that prevent help seeking in this group.

While illness perceptions explain a modest but significant amount of variance in carer outcomes, there are important implications for interventions. It might be possible to design interventions to target carers' illness perceptions and coping as these are potentially modifiable. The purpose would be to minimise poor outcomes in these carers to reduce distress and maximise quality of life and could indirectly benefit stroke survivors. The preliminary results of this study indicate that the illness perceptions most individually predicting poor outcomes are emotional representations, attributions to a psychosocial cause and perceptions of poor treatment control. Greater attention to these illness perceptions need to be made. It will be important not only to examine the carer's

emotional representations of health threats but to consider the beliefs that carers have about the stroke survivors' emotional representations. It will also be important to explore carers' attributional beliefs about stroke and assisting them to develop a greater understanding of helpful treatments or interventions. With respect to treatment control, it will be important to engender realistic hope about treatments for the stroke survivor but not to create unrealistic expectations. This may also be a valuable way of helping carers to feel more supported. As greater use of passive coping was associated with poorer outcomes, interventions to enhance alternative means of coping that might be more adaptive could be helpful. This is also likely to require provision of sources of support.

### **Future Research**

The limitations of the current study indicate that similar research is needed to ensure reliability of the findings. Given that emotional representations and attributions to a psychosocial cause were associated with greater distress in carers and greater treatment control was related to better psychological well-being and better social relationships, it will be important to investigate the possible explanations which may underlie these relationships. One means could be to conduct qualitative research which might allow us to unpack the meaning of these relationships. Exploration of relationships between each of the illness perceptions and with coping might enable a clearer understanding of whether, as proposed by the SRM, logical relationships exist between illness perceptions, coping and outcomes among carers of stroke survivors.

While this study has not explored the impact of carers' illness perceptions on stroke survivors, this might be an avenue to pursue, particularly if causal attributions are involved. If carers' illness perceptions impact on carer outcomes then it is realistic to assume that they could also influence stroke survivor outcomes. Research in myocardial infarction, for example, has found that spousal causal attributions are associated with patient outcomes (Weinman et al., 2000). The interaction of carer illness perceptions with those of the stroke survivor could also be worthwhile exploring.

It would be valuable to conduct longitudinal studies to obtain a greater understanding of the directions of relationships and to understand whether the relationships between illness perceptions and outcomes change over time. Finally, more research is needed to explore other factors, such as social support, which may explain aspects of carer distress and poor quality of life that illness perceptions and coping did not account for.

## **Conclusion**

This research has indicated a significant role of illness perceptions and coping in distress and aspects of quality of life in carers of stroke survivors. Despite limitations of the study, there are some important implications for potential interventions. Psychological interventions targeted at carer beliefs and coping may help to have a positive impact on stroke carers' distress and quality of life and on stroke survivors lives. More research is needed in this area to understand the complexities underlying illness perceptions in carers.

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### **Part 3: Critical Appraisal**

# **Critical Appraisal**

## **Introduction**

Stroke was an area that I wanted to research as it is a condition that is often unexpected and sudden. The occurrence of stroke can lead to dramatic changes in the stroke survivor's function, and recovery can be extremely varied. Unlike some other conditions, stroke can directly affect physical, cognitive and emotional functioning. The potential enormity and speed of its impact gives stroke survivors little time to adapt to their new situation.

Family members are also faced with these sudden and global changes and may have little choice in becoming a carer. Often family members have little or no prior experience of caring for someone with such potentially complex and multifaceted difficulties. As the effects of stroke are often longstanding, carers are likely to be involved in supporting the stroke survivor on a long-term basis. There are many additional challenges that carers face when stroke survivors return to the community. For example, they may have to give up work to care for the stroke survivor, which could have serious financial implications. Furthermore, they may have an increased burden of physical care and also less time for social activities and self-care. These represent only some of the ongoing issues that carers have to manage.

When conducting research about a training programme for carers of people with dementia, it struck me that while carers reported benefits of attending such a group,

there were still individuals who felt isolated, unsupported and did not prioritise their own needs. This suggested to me that we have to go beyond carer training programmes, which are largely educational in nature and may not reach those in most need. It is essential to consider how we might best be able to understand carers' difficulties and then think about meeting their needs more effectively. Psychological interventions based on a good understanding of the processes maintaining problems for the carer are likely to be more helpful than generic educational programmes that do not necessarily target individual carers' needs.

There are many reasons why carers' needs should be foremost in service providers' awareness. Carers that suffer from distress and poor quality of life may impact negatively on stroke survivors' physical, social and emotional well-being, which could also affect their rehabilitation. Carers can also play a direct role in rehabilitation. If there is a breakdown of the carers' relationships with others and with the stroke survivor, this could make it difficult for stroke survivors to continue to live in their own home. Additionally, carers experiencing difficulties need support in their own right. If services do not provide carers with adequate support to try to reduce carer distress and increase their quality of life, it may have an adverse effect on service demands. In carrying out this research, it was hoped that a greater understanding of factors influencing stroke carer outcomes could be gleaned. This might not only remind health professionals of their needs but may provide us with targets for possible interventions to help them. Through working in health and neurological settings I became interested in beliefs that carers held about the stroke survivors' illness and how these might influence their own outcomes.

The main objective of this study was therefore to investigate the role of illness perceptions and coping in distress and quality of life in carers of stroke survivors. The results indicated that illness perceptions accounted for variance in carer distress, psychological quality of life and social relationships, over and above carer, stroke survivor and illness characteristics. Emotional representations and belief in a psychosocial cause both independently predicted greater distress in carers. The illness perception of greater treatment control was independently associated with greater psychological and social quality of life. Coping added significant variance in psychological and social quality of life with less use of passive coping independently predicting better psychological well-being and better social relationships. Possible interpretations of these findings and other results have been discussed (see discussion of empirical paper).

This critical appraisal will explore the main strengths and some of the limitations of different aspects of the research not previously discussed. Some areas mentioned previously in the empirical paper will be elaborated here. Additional implications and directions for further research will also be discussed.

## **Strengths and Limitations**

### *Groundwork*

One aspect of this study which has been neglected in previous stroke carer research was carer quality of life. Much of the literature has, until now, focused on emotional outcomes in stroke carers and therefore this study had the potential to widen our knowledge of stroke carer outcomes. A frequently used quality of life measure is the

SF-36 Health Survey (Ware and Sherbourne, 1992), which assesses eight dimensions of health status. One concern identified at the early stages of the research process was that, although suitable for use in an interview format, the SF-36 was problematic in an older population when participants were required to complete the measure themselves (Hayes, Morris, Wolfe & Morgan, 1995; Lyons, Perry & Littlepage, 1994). The key problems found were consistent missing data and also several questions that older adults did not feel were applicable to their situation. Given that the current study was using postal questionnaires for carers to complete and that many carers were likely to be older adults, this could have been potentially problematic. Consequently, it was decided to search for an alternative measure that might not have such problems. The WHOQOL-BREF (The WHOQOL Group, 1998) was therefore chosen to assess quality of life. It is a brief measure that is relatively easy to complete and has no known problems in older adults. This problem highlighted to the researcher the importance of targeting measures that were appropriate, not just for the research question, but also for the intended sample and the methodology employed.

The researcher was given the opportunity to pilot the questionnaire pack, in a small number of carers, as part of service user involvement. Carers were able to provide the researcher with helpful feedback concerning the size, wording and layout of the questionnaires. This pilot study led to minor modifications of some of the measures and the omission of one, which carers found difficult to complete, and was deemed to add too much burden. This gave the researcher the opportunity to ensure that carers agreeing to complete this study were not overburdened and not made to feel distressed by taking

part in the study. Although there were questions that the researcher wanted to explore, it was recognised that the welfare of the participant should always be paramount.

### *Sample*

As mentioned in the discussion of the empirical paper, the sample size was smaller than desired. To gain access to the target sample of carers, it was first necessary to contact the stroke survivor, asking them whether they would pass on an information sheet and consent form to their carer, if they had one. There were various reasons why stroke survivors might not pass this on. They may have felt that the carer was too distressed, unwell or they did not want them to be bothered by the study. Alternatively, they could have felt that, although they had a relative who helped them, this did not necessarily mean they were a carer. Additionally, the study revealed there were some stroke survivors who were not able to identify someone as their carer. Of those carers who were given the information sheet, only a small percentage declined. This indicated that, although sample size was smaller than hoped, a relatively large proportion of identified carers were willing to participate. This represents an important strength of the study. Therefore even though there were two points at which carers might not be selected for inclusion in the study (selection by stroke survivors and self-selection), a reasonably good response rate was achieved.

The achieved sample was not necessarily representative of all stroke carers in the community. It is feasible that those taking part in the study, either through stroke survivor selection or self-selection, could have been more distressed or had poorer quality of life than those not participating. Carers experiencing problems may be more

likely to participate in the research so that they can gain access to services or they may just want to share their difficult experiences. Conversely, it is possible that those taking part in the study were the least distressed or had better quality of life. These carers might be more inclined to participate because they may feel more able to cope and less overwhelmed by other demands. Details of distress and quality of life in those not taking part in the research is unknown and therefore it is not possible to compare participants with non-participants. Indeed, non-participants may have differed to participants in areas other than the outcome measures, which may be important to understand.

Although these concerns exist, one advantage of this study was that all stroke survivors referred to the stroke coordinator were contacted rather than just those referred for specific difficulties, either physical or emotional. Therefore, apart from stroke survivor or self-selection bias, this sample represents more of a community sample of stroke carers unlike some other previous studies.

It is however, acknowledged that there still remain limitations concerning how representative the sample might be of the general stroke carer population. For example, with one exception, this study did not contain individuals from ethnic minority groups. This may be partially attributed to the geographic area from which the sample was taken.

### *Measures*

As mentioned in the discussion of the empirical paper, some measures to assess certain constructs have unknown psychometric properties. As explained previously, using a

single question to ask carers whether stroke survivors had contacted a health professional for psychological difficulties (since their stroke) may not accurately reflect the number of stroke survivors experiencing such problems. As stated before it may only reflect visits to a health professional and there may be individuals who experience difficulties but do not contact a health professional about these. One reason might be that, in the presence of perhaps cognitive or physical difficulties that occur as a result of the stroke, emotional difficulties are incorrectly attributed to these. Subsequently stroke survivors may not seek help. This is similar to diagnostic overshadowing. Furthermore, it is possible that carers are not aware of the stroke survivor visiting a health professional about such problems and carers may therefore be inadvertently under-reporting difficulties. Another limitation is that there were no means of verifying whether the difficulties they were contacting a health professional for were regarding actual psychological difficulties or something else. Furthermore, stroke survivors that do contact a health professional may only be doing this because they have been persuaded to seek help by the carer. Therefore the number of stroke survivors contacting a health professional could be partly based on carer perceptions that the stroke survivor has a psychological difficulty that needs addressing.

Another problem that was mentioned previously is that some of the measures may be carer's perceptions of stroke survivor function rather than objective measures of this, a problem noted by others (Blake, Lincoln & Clarke, 2003). Hence, it would be useful to investigate whether carer ratings are comparable to more objective means of assessing the same dimensions. It would have perhaps been advantageous to have obtained objective data on stroke survivor functioning (e.g. physical ability, language, cognitive



function) through formal assessment by health professionals. For example, neuropsychological assessment would have given a clearer understanding of stroke survivors' cognitive function rather than relying on a questionnaire that enquired about key dimensions of cognitive independence. However, even neuropsychological assessment test results alone do not provide an accurate indication of how cognitive difficulties translate into real world functioning.

Additionally, it is possible that some of the measures are not assessing the constructs that we are hoping to examine. For example, the Speech Questionnaire looks at communicative disability rather than aphasia specifically. This could make findings from the current study more difficult to compare accurately with previous research.

As stated in the discussion of the empirical paper, the assessment of coping through checklists may be problematic because checklists are not sufficiently specific and can ignore personal characteristics (Hagger & Orbell, 2003). Coping is a very individual process, influenced by multi-faceted contextual factors surrounding the person and their system. It is possible that, by using the Brief COPE, important aspects of coping in stroke carer populations could have been missed, which could explain why coping did not correlate with more outcomes and did not account for more variance. Therefore investigation into alternative or additional means of assessing coping needs to take place. This may involve using behavioural methodologies.

In order to minimise burden on participants a limited number of measures were used. This consequently involved the omission of other measures that might have played an

important role in outcomes. For example, a measure of social support was initially included in the questionnaire pack but carers in the pilot study found it difficult to complete and stated that this made the questionnaire pack rather long. Factors such as social support could potentially have a mediating impact between illness perceptions, coping and outcomes and therefore might be important to investigate in the future. Although limited in the number of measures used, it was felt that a reasonably good range of variables were explored in this study. It was necessary to examine these, in addition to illness perceptions and coping, because previous research had suggested that certain carer, stroke survivor and illness characteristics were important determinants in carer outcomes.

In using the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), in this study, it was necessary to make some modifications to the wording to ensure it was suitable for carers of stroke survivors. While effort was made to check adaptation with one of the principal authors, the final adapted version did not undergo full psychometric evaluation. However, face validity of the measure was checked with carers in the pilot study and internal consistency, which was broadly comparable to the original revised version, was very good for all subscales. Additionally, Weinman, Heijmans & Figueiras (2003) reported that where carer versions of the Illness Perception Questionnaire have been evaluated psychometrically, results are acceptable but not quite as robust as original patient orientated versions.

An area of interest for this study was to examine carers' perceptions in relation to themselves and to the stroke survivor separately. Therefore two parallel versions of four

of the subscales were created (e.g. 'my relative's stroke health condition has major consequences on my life' and 'my relative's stroke health condition has major consequences on their life'). As there were already a large number of variables to be included for analysis and the two versions of all four subscales were strongly and positively correlated with each other, the parallel versions were combined.

However, further statistical analyses using paired samples t tests revealed that, although correlated, two of the four pairs were significantly different from each other. There was a significant difference between carers perception of the consequences of the stroke for themselves and their perception of the consequences of the stroke for the stroke survivor ( $t(71) = 3.549, p = .001$ ). Examination of the mean scores indicates that carers perceived the stroke to have greater consequences for the stroke survivor than for themselves. There was also a significant difference between carers' perceptions of how coherent their understanding of the illness was and how coherent they perceived it was for the stroke survivor ( $t(71) = -3.353, p = .001$ ). Examination of the means indicates that carers perceived themselves to have a more coherent understanding of the illness than the stroke survivor. There were no significant differences between the parallel versions of the personal control or emotional representation dimensions. These results suggest that the combined consequences and illness coherence scales each measure two closely related but different constructs.

A possible criticism relating to the measures used to look at carer outcomes could be that they do not adequately measure the constructs that this research has intended to focus on. With respect to assessing carer distress, it could be argued that the General Health

Questionnaire does not represent an accurate means of assessing distress, particularly given that a 12 item version was used. While brief versions of some of the questionnaires were used to reduce burden in the sample, critics might argue that it is not possible to determine whether an individual is distressed based on 12 questions. Similar criticisms might be applied to the WHOQOL-BREF, which is a more concise version of the WHOQOL-100, used to assess quality of life. While clearly this argument can be upheld and longer versions might allow researchers to obtain a clearer understanding of the construct under examination, there is nevertheless a trade off. For example, while a measure with a greater number of items in a scale tends to improve internal consistency, it is more likely to reduce compliance as it is less simplistic and more burdensome for participants to complete.

The inclusion of the General Health Questionnaire (12 item version) and WHOQOL-BREF were chosen as outcome measures for this study based on a range of criterion, including whether they were deemed to be relevant to the study in terms of the context of their use, their psychometric properties (which have been demonstrated as being good) and their ease of use by participants.

With respect to the use of the WHOQOL-BREF, it may be postulated that it is not possible for any quantitative measure to adequately assess the concept of quality of life. Proponents of this argument might suggest that such measures present a fragmented view of the concept. Certainly an individual's definition of quality of life is unique and very personal and thus the notion that a single 26 item measure can fully capture this is acknowledged as something that is difficult to achieve in its entirety. In measuring

quality of life the WHOQOL-BREF examines the individual's perception of how good, how completely or how satisfied they are about certain dimensions of their life including their physical health, their psychological well being, their social relationships and their environment. Therefore it is recognised that the understanding of quality of life that has been gleaned in this study is confined by the measure that is employed.

The use of quantitative structured measures is not the only means of understanding quality of life. Indeed, the use of qualitative methodologies may allow us to understand further the idiosyncratic underpinnings of quality of life, adding more depth to our appreciation of this construct in carers of stroke survivors. However, the role of a quantitative means of assessing quality of life may have still have certain benefits. For example, they can be used in clinical practice to allow clinicians to understand the areas of a person's life that are most affected and therefore to assist decisions in providing care. They can also be a useful means of evaluating the impact of interventions on different aspects of a person's life in both medical and psychological settings. While we can also use qualitative methodologies to examine these, they are less likely to be employed routinely due to their time consuming nature.

### *Design*

The means of accessing information about carers and stroke survivors was achieved by using quantitative self-report measures. This has several advantages such as allowing us to access a larger sample size, obtaining participants' views directly and enabling them to complete the questionnaires in their own time. However, there are a number of limitations with this type of design. As mentioned previously, participants' responses do

not necessarily equate to objective assessments and are flavoured by their perceptions. For some of the questionnaires in this study such as the IPQ-R, carer perceptions were intended and therefore this would have been desirable. Other criticisms of self-report methods have been raised (see Barker, Pistrang & Elliott, 2002, for an overview). The use of closed questions, used in this study, can be problematic for participants because it forces them to select an answer which may not accurately reflect their views. Indeed, in talking to carers, some had reported that they occasionally found it difficult to select an answer because their actual response was either different or between categories. In this respect it is also possible to lose richness of information. However, closed questions are easier to quantify and analyse. Alternative methodologies to examine illness perceptions could be used such as qualitative in-depth interviews, the use of a comparative group and even possibly experimental methodologies (some of these are discussed later).

### *Analysis*

In addition to the large number of variables entered for analysis (see discussion of empirical paper), a further issue is that for two of the five regression analyses, there were perhaps more predictor variables entered into the regressions than desired. There are different opinions about the minimum number of cases required for each predictor variable entered into the regression. Brace, Kemp & Snelgar (2003) stated that the absolute minimum should be five times as many participants as predictor variables. However, they also indicate that others have argued that it should be as high as 40:1 but that 10:1 is deemed acceptable. Although two of the regression in the current study did not achieve the ratio of 10:1, they were above the recommended minimum.

Several means of reducing the number of variables in the study were employed. The reduction in the number of variables was achieved by only including variables that have been found to be important in past research, in addition to the illness perception and coping variables of interest in this study. Additionally, the use of principal components analysis provided a means of reducing the number of variables. However, it is recognised that the sample size was smaller than desired with respect to using this method of data reduction. As the parallel versions of the IPQ-R dimensions were highly correlated these were combined. To further minimise unnecessary multiple testing, the two aims were explored in one single stepwise multiple regression analysis for each outcome variable. It is acknowledged that there is a possibility of obtaining spurious results due to multiple testing.

Due to some of the issues raised concerning the statistical analyses, results of the study should be viewed with caution. Replication of this study would be important to determine the reliability of the current findings.

### **Implications**

There are several theoretical and clinical implications from this research and the key ones have been discussed previously (see discussion of empirical paper).

In light of the current findings it would be appropriate to provide an appraisal of the SRM. As stated in the discussion of the empirical paper, while illness perceptions and coping were found to explain significant variance in distress and both psychological and social quality of life, there was still significant variance unexplained. Furthermore

neither illness perceptions nor coping were found to be predictors of physical or environmental quality of life. In terms of the SRM, it might therefore be argued that, on its own, it is not a sufficient model of understanding carer outcomes. Indeed, in the discussion of the empirical paper, it is suggested that other factors need to be considered. Nevertheless, this study has only focused on specific parts of the SRM, namely cognitive representations, emotional representations, coping and outcomes. Other aspects of the model, have tended to have been neglected in the research employing the SRM as a theoretical framework. For example, the illness stimuli proposed to contribute to the development of cognitive and emotional representations and also appraisal of coping. These are important aspects of the model which need investigation before it is possible to fully appraise the SRM.

The development of the IPQ-R has provided a means of assessing emotional representations and the results of the current study indicate that, consistent with the model, emotional representations play an important role in carer distress. This is an important component of the SRM which has, until more recently, received little attention compared to the cognitive representations.

The utility of the SRM in understanding patient outcomes has been well investigated in previous research. At the present time, previous research and the results from the current study indicate that the SRM can also offer a framework for understanding outcomes in carers. However, it will be important to explore other aspects of the model in further research to obtain a clearer appreciation of its application as a whole to carers.



As discussed previously, high levels of distress were found in carers of stroke survivors but comparatively fewer carers contact a health professional for such difficulties. This could indicate a need to investigate factors driving or preventing help seeking to allow services to access those experiencing problems. Explanations for help seeking behaviour could be based around carers' illness perceptions about their own distress. Carers experiencing distress may view it as a symptom of their caring role rather than symptomatic of distress. Hence, symptoms of distress form their caring identity. Carers may feel that there is little that can be done to help them with their own difficulties and therefore they may not seek help for these. These beliefs might reflect perceptions of poor control over their difficulties. Furthermore, carers may perceive negative consequences of seeking help. For example, they may believe that seeking help might indicate that they are not coping with their caring role. They may also subjugate their own needs because they believe that it is the stroke survivor that should receive help from services rather than themselves.

With respect to implications for interventions, it might be possible to design interventions to target carers' illness perceptions and coping as these are potentially modifiable and could help to minimise poor outcomes in carers and even stroke survivors. At the current time, there are relatively few studies that have explicitly drawn on the SRM to develop interventions for patients with chronic illness, although this is increasing (see Petrie, Broadbent & Meechan, 2003, for an overview). For example, Petrie, Cameron, Ellis, Buick & Weinman (2002) carried out a brief inpatient intervention to modify inaccurate negative illness perceptions in patients with myocardial infarction. They found that those receiving this intervention showed positive

changes in patients' illness beliefs, faster rate of return to work and lower rates of angina symptoms compared to those receiving routine care. While this type of research is still in the early stages, there have been some promising findings.

### **Future Research**

The limitations of the current study indicate that, firstly, similar research is needed to ensure reliability of the findings. It would be important to try to obtain a larger sample size and to endeavour to include carers of stroke survivors that are more demographically diverse. Also, consideration needs to be given to carers of stroke survivors who may be at later points in their recovery.

As stated before, longitudinal studies are needed to understand more clearly the directions of relationships and to identify whether the relationships between illness perceptions and outcomes change over time. More specifically, this may allow us to understand whether illness perceptions change over time in stroke carers and also whether illness perceptions at the acute stage of stroke are predictive of later stroke carer outcomes. With respect to other aspects of design, it might be helpful to compare stroke carers' illness perceptions to other carer groups or even non-carer groups. Another type of research design that might be constructive could be the use of experimental methodology. For example, it may be possible to develop interventions to target unhelpful illness perceptions. This could help us to obtain a greater understanding of causal relationships between illness perceptions and outcomes.

More research is needed to explore other factors which may explain aspects of carer distress and poor quality of life that may not be explained by illness perceptions or coping, such as the role of social support or carers' appraisal of their coping efforts. In exploring these other constructs careful attention would need to be paid to the means of assessing them. For example, there is currently little research that has focused on the nature of appraisals or on ways in which we could measure these, yet this forms an important component of the SRM.

## **Conclusion**

This exploratory piece of research has yielded some interesting findings with respect to the role of illness perception and coping in carer outcomes. Despite important strengths of the current study and the potential theoretical and clinical implications, there are also a number of limitations which indicate that findings should be viewed cautiously. There are many stimulating avenues for further research and one of the first steps would be to test the findings of the current study. The SRM provides a useful framework to investigate illness perceptions in stroke carers. It offers promising opportunities to understand other important factors influencing carer outcomes and the possibility of developing interventions that might facilitate a more positive outcome for carers. While this study has focused specifically on carers of stroke survivors, we must consider that caring is not simply an individual process but it takes place within a wider complex system and involves multifarious factors that we are only just beginning to understand.

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## Appendices

### Appendix I

#### Frequency and Percentage of Responses from Stroke Survivors and Carers

	Frequency (%)
Stroke survivors that could not identify a carer	20 (10.1)
Stroke survivors that did not wish to pass on the information sheet	30 (15.2)
Stroke survivors that declined for another reason (e.g. carer unwell)	7 (3.5)
Stroke survivors who declined, giving no reason	10 (5.1)
Patients that had died since being contacted	3 (1.5)
Stroke survivors that did not respond to initial or reminder letters	30 (15.2)
Carers declining participation in study	16 (8.1)
Carers consenting to participate in the study	82 (41.4)
<i>Carers who returned completed questionnaires</i>	<i>72 (36.4)</i>
<i>Carers not returning questionnaires</i>	<i>10 (5.0)</i>

## Appendix II

### Power Calculation:

In order to have 80% power to detect a correlation of 0.28 at alpha of 0.05, a sample size of 98 was required. The correlation of 0.28 was obtained from McClenahan & Weinman's (1998) study and represents the weakest significant correlation that they reported. This correlation was between the illness perception of timeline and distress as measured by the Illness Perception Questionnaire (IPQ) (Weinman et al., 1996) (amended) and General Health Questionnaire (GHQ-12) (Goldberg, 1988) respectively. A sample size of 98 was therefore aimed for although this was not reached as a sample size of 72 was achieved.



**Mid and South Buckinghamshire Local  
Research Ethics Committee**

Wycombe Hospital  
C/o Clinical Effectiveness Dept.  
Chiltern Medical Education Centre  
Queen Alexandra Road  
High Wycombe  
Buckinghamshire  
HP11 2TT  
Tel/Fax: (01494) 42 6370

**Appendix III**

05 November 2004

Dear Miss Waller,

**Full title of study:** *Using Illness Perceptions to understand Coping and Quality of Life in carers of people who have had a stroke*  
**REC reference number:** 04/Q1607/46  
**Protocol number:** 1

Thank you for your letter of 26 October 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chairman.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research site:

Site: Vale of Aylesbury Primary Care Trust  
Principal Investigator: Miss Denise C Waller

**Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document Type: Application  
Version: 1  
Dated: 08/09/2004  
Date Received: 24/09/2004

Document Type: Investigator CV  
Version:  
Dated: 05/09/2004  
Date Received: 24/09/2004

Document Type: Investigator CV  
Version:  
Dated: 05/09/2004  
Date Received: 24/09/2004

Document Type: Protocol  
Version: 1  
Dated: 05/09/2004  
Date Received: 24/09/2004

Document Type: Letter from Sponsor  
Version:  
Dated: 09/09/2004  
Date Received: 24/09/2004

Document Type: Peer Review  
Version:  
Dated: 08/12/2003  
Date Received: 24/09/2004

Document Type: Copy of Questionnaire  
Version: 2  
Dated: 21/10/2004  
Date Received: 02/11/2004

Document Type: Letters of Invitation to Participants  
Version: 2  
Dated: 21/10/2004  
Date Received: 02/11/2004

Document Type: Letters of Invitation to Participants  
Version: 2  
Dated: 21/10/2004  
Date Received: 02/11/2004

Document Type: GP/Consultant Information Sheets 1  
Version:  
Dated: 05/09/2004  
Date Received: 24/09/2004

Document Type: Participant Information Sheet  
Version: 1  
Dated: 05/09/2004  
Date Received: 24/09/2004

Document Type: Participant Consent Form  
Version: 1  
Dated: 05/04/2004  
Date Received: 24/09/2004

Document Type: Response to Request for Further Information  
Version:  
Dated: 26/10/2004  
Date Received: 02/11/2004

Document Type: Supervisors CV  
Version:  
Dated: 05/09/2004  
Date Received: 24/09/2004

### **Management approval**

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

### **Notification of other bodies**

We shall notify the research sponsor and the Vale of Aylesbury Primary Care Trust that the study has a favourable ethical opinion.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**Dr Susan Kelly, D Phil FRCP FRCPATH**  
**Consultant Haematologist**  
**Chairman**  
**Mid & South Buckinghamshire LREC**

*Enc: Standard approval conditions SL-AC2*

Vale of Aylesbury



Primary Care Trust

Verney House  
Gatehouse Road  
Aylesbury  
Bucks  
HP19 8ET

Denise Waller  
Sub-department of Clinical Health Psychology  
University College London  
Gower St  
London  
WC1E 6BT

Wednesday, 10 November 2004

Dear Denise

**Re: "Using Illness Perceptions to understand Coping and Quality of Life in carers of people who have had a stroke."**

Thank you for your LREC approval letter, your project now has full approval, and you may start your research.

On behalf of the VOA R&D Steering Group I would like to wish you every success with your project. I look forward to hearing from you on completion of your project, when we will require a final report, including an account of how the funding from the PCT has been spent.

Yours sincerely

Diana Moule  
Research Management and Governance Administrator

Cc Dr John Pimm

**Rayners Hedge  
Croft Road  
Aylesbury  
Buckinghamshire  
HP21 7RD**

Dear

We are carrying out a research study at Rayners Hedge. This is looking at the impact of stroke on relatives/carers. This research is being carried out by Denise Waller (Trainee Clinical Psychologist) with Dr. John Pimm (Consultant Clinical Psychologist).

We would like to invite your relative/carer to take part in the study. This would involve your relative/carer completing one set of questionnaires. We are writing to ask whether you could pass on the enclosed information sheet and consent form to the person who you consider to be most involved in providing you with support/care. This could be a relative, partner or friend but not a paid/professional carer. They must be an adult (aged 18 or over).

The information sheet explains what the study is about and what is involved. Please feel free to read this yourself before deciding whether to pass it on. If the person who you pass the information sheet on to chooses to take part, their responses will be confidential. We have written to your GP informing them that we have contacted you to invite your relative/carer to take part in the study.

If you cannot identify someone who you consider to be most involved in providing you with support/care or if you do not wish to pass on the

information sheet, please complete and return the enclosed slip. This will ensure that we do not contact you about this study again.

Please feel free to ask any questions that you want about this study. You can contact Denise Waller or myself at Rayners Hedge on

Thank you very much for your time.

Yours sincerely

Clare Cheney  
Community Stroke Nurse/Coordinator

## **REPLY SLIP**

*Please complete and return this slip if you do not pass on the enclosed information sheet to the person who you consider provides you with most support/care. If you complete this slip we will not contact you about this study again.*

**Your Name (please print in block capitals)**

---

*Please tick which box applies below:*

**I am not able to identify someone that is involved in providing me with support/care**

☐

**I would prefer not to pass on the letter inviting my relative/carer to take part in the study**

☐

## **INFORMATION SHEET**

### **Coping and Quality of Life in Stroke Carers**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the purpose of the study?**

We are interested in looking at the impact of stroke on relatives/carers. In particular, we are interested in finding out whether relative's/carer's views of stroke and ways of coping affect their well being.

#### **Why have I been chosen?**

We have written to all people that have had a stroke who have been referred to the Community Stroke Nurse/Coordinator (Clare Cheney) who is based at Rayners Hedge, Community Neurological Rehabilitation Service. We have asked each person if they could pass on this information sheet to the person who they consider provides the most support/care for them and they have passed this on to you.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that the person who has had the stroke receives.

#### **What will happen to me if I take part?**

The study would involve you completing some written questionnaires on one occasion only. The questionnaires ask you about basic information concerning the current difficulties of the person who has had the stroke, your views about their stroke, coping strategies, distress, quality of life and basic information about you and your relative/person you care for (e.g. age, occupation, time since stroke etc). It should take you about 60 minutes to fill in the questionnaires. If you decide to take part in the research, we will send you the questionnaire pack to the address that you provide on the consent form. You can fill in the questionnaires at home and return them in a stamped addressed envelope that we will provide. If you would like someone to help you to fill in the questionnaires then we can arrange for someone to either give you assistance over the telephone or to meet with you to do this at a convenient time.

#### **What are the possible disadvantages and risks of taking part?**

There are no risks involved in taking part. All the information that we obtain will be confidential. Your name will not be on any of the questionnaires. If any of the questionnaires raise concerns or distress for



you please contact Denise Waller (the researcher and Trainee Clinical Psychologist) or Clare Cheney (Community Stroke Nurse/Coordinator) both at Rayners Hedge on 01296 393319.

**What are the possible benefits of taking part?**

We hope that this kind of research will help us to identify which relatives/carers are likely to become most affected by their relative's stroke. This could enable us to make suggestions about the type of services that might help relatives/carers of people who have had a stroke.

**Will my taking part in the study be kept confidential?**

All information which is collected about you or the person who has had a stroke will be strictly confidential and kept secure. Any information that might identify you personally, such as names and addresses, will be removed before publication so that you cannot be recognised from it.

**What will happen to the results?**

The information collected will be analysed and a report will be written summarising the findings. A report may be published in a scientific journal and in relevant stroke or carer magazines in a year or two. It will not be possible to identify you or anyone else in these. All data that we have collected will be kept by us for 5 years and kept securely. Data from one of the questionnaires which asks about quality of life will be shared with the research group who have allowed us to use the questionnaire for this study. This data will be used to help the research group in the development of the questionnaire. It will remain confidential.

**Who is organising and funding the research?**

The study is being carried out by Denise Waller as part of her doctorate in Clinical Psychology at University College London and with Dr. John Pimm (Consultant Clinical Psychologist) at Rayners Hedge. The research is supported by the Doctoral course at University College London and by the Community Neurological Rehabilitation Service of the Vale of Aylesbury Primary Care Trust. Funding for this study has been obtained from University College London and also the Vale of Aylesbury Primary Care Trust Research and Development Steering Group. This funding is to cover the costs needed to run the project such as photocopying, envelopes and postage.

**Who has reviewed the study?**

The study has been reviewed by the Mid and South Buckinghamshire Local Research Ethics Committee and the Vale of Aylesbury Primary Care Trust Research and Development Steering Group

**Contact for further information**

Please feel free to ask any questions that you want about this study. You can contact Denise Waller (Trainee Clinical Psychologist) or Clare Cheney (Community Stroke Nurse/Coordinator) at Rayners Hedge on

If you do agree to take part in the study, please complete the attached consent form and return it in the stamped addressed envelope provided. This information sheet is for you to keep and when we send the questionnaire pack we will send you a copy of the signed consent form for you to keep.

If you do not wish to take part in this study, please circle the appropriate response indicating this on the consent form and return in the stamped addressed envelope provided. This will ensure that we do not contact you or the person who has had the stroke again about this study.

**THANK YOU FOR READING THIS SUMMARY AND FOR TAKING PART IN THE STUDY SHOULD YOU DECIDE TO DO SO**

Appendix VI

Clinical Services Directorate  
ADULT SERVICES

Participant Identification Number:

Rayners Hedge  
Croft Road  
Aylesbury  
Buckinghamshire  
HP21 7RD

**CONSENT FORM**

**Coping and Quality of Life in Stroke Carers**

If you **do not** wish to take part in the study please complete items 1 and 5 (please note that we ask for the name of the person who has had the stroke only so that we can match their name to this form. This is to ensure that we do not contact them again about this study. Your decision not to take part in this study will not affect the care of the person who has had the stroke)

1. I do not wish to take part in the study

Please initial box

☐

If you **do** wish to take part please complete **all** the items below (items 2-6)

2. I confirm that I have read and understand the information sheet dated ..... for the above study and have had the opportunity to ask questions.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and that this will not affect the medical care of the person who has had the stroke.
4. I agree to take part in the above study

Please initial box

☐☐☐

Your Name \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

Name of Researcher \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

5. So that we can match the name of the person who has had the stroke to this form, please write their name here

Their name \_\_\_\_\_

6. If you have agreed to take part in the study please write your full postal address and telephone number in the space provided so that we can send you the questionnaires

Your address \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Your telephone number \_\_\_\_\_ Postcode \_\_\_\_\_

Please tick this box if you have taken part in any other research studies within the past 6 months

159 ☐

Appendix VII

Clinical Services Directorate  
ADULT SERVICES

Rayners Hedge  
Croft Road  
Aylesbury  
Buckinghamshire  
HP21 7RD

Dear Dr.

We are writing to inform you that we have written to your patient \_\_\_\_\_ ;  
DOB: \_\_\_\_\_ to invite their relative to take part in a research study that we are  
carrying out at Rayners Hedge. This research is being carried out by Denise Waller  
(Trainee Clinical Psychologist) with Dr. John Pimm (Consultant Clinical Psychologist).  
We are interested in looking at the impact of stroke on relatives/carers. In particular, we  
are interested in finding out whether relatives'/carers' views of stroke and ways of coping  
affect their well being. The research would involve their relative/carer completing some  
questionnaires. We hope that this kind of research will help us to identify which  
relatives/carers are likely to become most affected by their relative's stroke. This could  
enable us to make suggestions about the type of services that might help relatives/carers of  
people who have had a stroke.

We have asked your patient to pass on an information sheet and consent form to the person  
who they consider to be most involved in providing them with support/care. This could be  
a relative, partner or friend but not a paid/professional carer. They must be an adult (aged  
18 or over). The information sheet explains what the study is about and what is involved. I  
have enclosed a copy of this information sheet for your reference.

If you would like to discuss this further or have any concerns about this, please do not  
hesitate to contact either Clare Cheney (Community Stroke Coordinator) or Dr. John Pimm  
(Consultant Clinical Psychologist) at Rayners Hedge on

Yours sincerely

Clare Cheney  
Community Stroke Nurse/Coordinator

**Rayners Hedge  
Croft Road  
Aylesbury  
Buckinghamshire  
HP21 7RD**

**Dear**

You may recall that we wrote to you some time ago about a study that we are carrying out at Rayners Hedge. We invited your relative to take part in this. This research is being carried out by Denise Waller (Trainee Clinical Psychologist) with Dr. John Pimm (Consultant Clinical Psychologist). We are interested in looking at the impact of stroke on relatives/carers.

As we did not receive a reply from you, we are writing to ask whether you could pass on the enclosed information sheet and consent form to the person who you consider to be most involved in providing you support/care. This could be a relative, partner or friend but not a paid/professional carer. They must be an adult (aged 18 or over).

The information sheet explains what the study is about and what is involved. The research would involve your relative/carer completing some questionnaires. If the person who you pass the information sheet on to chooses to take part, their responses will be confidential. We have written to your GP informing them that we have contacted you to invite your relative/carer to take part in the study.

If you cannot identify someone who you consider to be most involved in providing you support/care or if you do not wish to pass on the

information sheet, please complete and return the enclosed slip. This will ensure that we do not contact you about this study again.

Please feel free to ask any questions that you want about this study. You can contact Denise Waller or myself at Rayners Hedge on

Thank you very much for your time.

Yours sincerely

Clare Cheney  
Community Stroke Nurse/Coordinator

## **REPLY SLIP**

*Please complete and return this slip if you do not pass on the enclosed information sheet to the person who you consider provides you with most support/care. If you complete this slip we will not contact you about this study again.*

**Your Name (please print in block capitals)**

---

*Please tick which box applies below:*

**I am not able to identify someone that is involved in providing me with support/care**

☐

**I would prefer not to pass on the letter inviting my relative/carer to take part in the study**

☐

**Appendix IX**

**Clinical Services Directorate  
ADULT SERVICES**

**Rayners Hedge  
Croft Road  
Aylesbury  
Buckinghamshire  
HP21 7RD**

Dear

Thank you for agreeing to take part in the study. Please find enclosed a questionnaire pack for you to complete. It should take you approximately 60 minutes to complete these. Once you have filled all of them in please return them in the stamped addressed envelope provided. We also enclose a copy of the consent form which you signed for you to keep.

If you require any help with completing the questionnaires please contact Denise Waller on [redacted] who can either arrange to help you over the telephone or can meet you at a convenient time to complete the questionnaires together, whichever you prefer. Please contact us if, for any reason, you require further questionnaires.

If you have any concerns or become distressed when completing the questionnaires, you can either contact Denise Waller (Trainee Clinical Psychologist and the researcher) or Clare Cheney (Community Stroke Nurse/Coordinator) at Rayners Hedge on [redacted].

We are very grateful for your help and we hope that this research will help us to understand which relatives/carers are likely to become most affected by their relative's stroke. This may help us to consider the type of service that we might be able to provide to help improve relative's/carer's quality of life.

Thank you for your time.

Yours sincerely

Denise Waller  
Trainee Clinical Psychologist  
University College London/Rayners Hedge

**Appendix X**

**Clinical Services Directorate  
ADULT SERVICES**

**Rayners Hedge  
Croft Road  
Aylesbury  
Buckinghamshire  
HP21 7RD**

Dear

You may recall that we contacted you recently about taking part in a research study that we are carrying out at Rayners Hedge. You kindly agreed to take part in this study by returning the consent form and we then sent you the questionnaires.

As we have not received these questionnaires back, we are writing to ask whether you would still like to take part in the study and if so, whether you could return the questionnaires to us at your earliest convenience.

If you require any help with completing the questionnaires please contact Denise Waller on \_\_\_\_\_ who can either arrange to help you over the telephone or can meet you at a convenient time to complete the questionnaires together, whichever you prefer. Please contact us if, for any reason, you require further questionnaires. We would be more than happy to send these and a stamped addressed envelope for your reply.

If you have any concerns or become distressed when completing the questionnaires, you can contact either Denise Waller (Trainee Clinical Psychologist and the researcher) or Clare Cheney (Community Stroke Nurse/Coordinator) at Rayners Hedge on \_\_\_\_\_

We would be very grateful for your help. Thank you for your time.

Yours sincerely

Denise Waller  
Trainee Clinical Psychologist  
University College London/Rayners Hedge



## ABOUT YOU AND YOUR RELATIVE

Please take a few minutes to complete the questions below which are about you and your relative who has had the stroke. These questions are important to help us to ensure that (as far as possible) we have included a range of people from different backgrounds/circumstances. Please answer all questions and, unless stated otherwise, tick one box only.

### ABOUT YOU

**1. Are you currently:**

Working Full-time  
Working Part-time  
Retired  
Other


If other, please specify \_\_\_\_\_

If you are working, please state your occupation \_\_\_\_\_

**2. Your ethnicity:**

White  
Black  
Asian  
Other


If other, please specify \_\_\_\_\_

**3. Since your relative first had a stroke, have you visited your GP or other health professional for any major health problems yourself?**

Yes  
No


If Yes, what was the problem that you were seeking help for? \_\_\_\_\_

**4. Did you ever contact your GP or other health professional for anxiety, depression or other psychological difficulties before your relative first had a stroke?**

Yes  
No


If Yes, what was the problem that you were seeking help for? \_\_\_\_\_

5. Have you contacted your GP or other health professional for anxiety, depression or other psychological difficulties since your relative first had a stroke?

Yes


No

If Yes, what was the problem that you were seeking help for? \_\_\_\_\_

6. What is your relationship to the person who has had the stroke? Are they:

Your spouse/partner


If spouse/partner, how many years have you been in the relationship? \_\_\_\_\_

Your mother/father


Your son/daughter


Your brother/sister


Your grandparent


Other

If other, please specify \_\_\_\_\_

7. What kinds of care do you usually provide for the person who has had the stroke (over and above what you would normally do for someone living with you)? (Please tick all those boxes that apply). Do you usually help with...

a) Personal Care (e.g. dressing, bathing, washing, shaving, feeding, using the toilet)?


b) Physical Help (e.g. with walking, getting up and down stairs, getting in/out bed)?


c) Helping with paperwork or financial matters (e.g. writing letters, paying bills)?


d) Other Practical Help (e.g. preparing meals, doing their shopping, laundry)?


e) Keeping him/her company (e.g. visiting, sitting with, reading to, talking to)?


f) Taking him/her out (e.g. taking out for a walk/drive, taking to see friends/relatives)?


g) Giving Medicines (e.g. making sure he/she takes pills, giving injections)?


h) Keeping an eye on him/her to see if he/she is all right?


i) Other help? If other help, please specify \_\_\_\_\_


8. On average, how long do you spend each week looking after or helping the person who has had the stroke (that is doing the things you have mentioned in question 7)?

0-19 hours per week


20-34 hours per week


35-49 hours per week


50-99 hours per week


100 or more hours per week


Other

If other, please specify \_\_\_\_\_

9. Does the person who has had the stroke receive a professional care package (e.g. care provided by health or social care agencies)?

Yes

No

Don't Know


If the person does have a professional care package, about how many hours a week do they receive?

\_\_\_\_\_ hours

## **ABOUT YOUR RELATIVE**

10. How old is your relative? \_\_\_\_\_ years

11. Your relative's sex:

Male

Female


12. Your relative's ethnicity:

White

Black

Asian

Other


If other, please specify \_\_\_\_\_

13. Is your relative currently:

Working Full-time

Working Part-time

Retired

Other


If other, please specify \_\_\_\_\_

If they are working, please state their occupation \_\_\_\_\_

14. Is your relative currently:

Living at home with you

Living at home with another relative

Living at home alone

Living in a residential/nursing home

Other


If other, please specify \_\_\_\_\_

15. How many strokes has your relative had? \_\_\_\_\_

If your relative has had more than one stroke, how long ago was their first stroke? \_\_\_\_\_

16. To your knowledge, does your relative have TIA's (mini-strokes)?

Yes	
No	
Don't know	

17. How long has it been since your relative had their (most recent) stroke?

Less than 6 months ago	
Between 6 -12 months ago	
Between 1 – 2 years ago	
More than 2 years ago	

18. What side of their body did/does your relative experience weakness/paralysis in:

Left	
Right	
Both	
Neither	
Other	

If other, please explain \_\_\_\_\_

19. Since your relative first had a stroke, have they contacted their GP or other health professional for anxiety, depression or other psychological difficulties?

Yes	
No	

If Yes, what was the problem that they were seeking help for? \_\_\_\_\_

20. Before your relative first had a stroke, did they ever contact their GP or other health professional for anxiety, depression or other psychological difficulties?

Yes	
No	

If Yes, what was the problem that they were seeking help for? \_\_\_\_\_

# BARTHEL INDEX

The items below ask about activities of everyday life that some people may experience difficulties with following a stroke. For each item please write the number in the appropriate box that corresponds with what best describes what your relative (the person who has had a stroke) has done over the past 4 weeks. It is important that your ratings are about what the person has done/does rather than what they may be able to do. By independent we mean not requiring any help, physical or verbal, however minor.

1. BOWELS	0 = Incontinent 1 = Occasional accident (once a week) 2 = Continent	<input type="checkbox"/>
2. BLADDER	0 = Incontinent/Catheterised 1 = Occasional accident (max 1 per day) 2 = Continent (for over 7 days)	<input type="checkbox"/>
3. GROOMING	0 = Needs Help with personal care 1 = Independent (face/hair/teeth/shaving)	<input type="checkbox"/>
4. TOILET USE	0 = Dependent 1 = Needs some help but can do something alone 2 = Independent	<input type="checkbox"/>
5. FEEDING	0 = Unable 1 = Needs help cutting/spreading butter etc 2 = Independent	<input type="checkbox"/>
6. TRANSFER (bed to chair and back)	0 = Unable 1 = Major help (1-2 people, physical) 2 = Minor help (verbal or physical) 3 = Independent	<input type="checkbox"/>
7. MOBILITY	0 = Immobile 1 = Wheelchair independent, including corners 2 = Walks with help of 1 person (verbal/physical) 3 = Independent (but may use aid, e.g. stick)	<input type="checkbox"/>
8. DRESSING	0 = Dependent 1 = Needs help, but can do about half unaided 2 = Independent (including buttons, zips, laces etc)	<input type="checkbox"/>
9. STAIRS	0 = Unable 1 = Needs help (verbal or physical, carrying aid) 2 = Independent up and down	<input type="checkbox"/>
10. BATHING	0 = Dependent 1 = Independent (or in shower)	<input type="checkbox"/>

## EXTENDED ADL INDEX

The following questions are about everyday activities. Please answer by ticking **ONE** box for each question. Please record what your relative (the person who has had a stroke) has **ACTUALLY** done in the last 4 weeks.

	<b>DID THEY:</b>	<b>Not at all</b>	<b>With Help</b>	<b>Alone with difficulty</b>	<b>Alone easily</b>
<b><u>MOBILITY</u></b>					
1	Walk around outside?				
2	Climb Stairs?				
3	Get in and out of the car?				
4	Walk over uneven ground?				
5	Cross roads?				
6	Travel on public transport?				
<b><u>IN THE KITCHEN</u></b>					
7	Manage to feed themselves?				
8	Manage to make themselves a hot drink?				
9	Take hot drinks from one room to another?				
10	Do the washing up?				
11	Make themselves a hot snack?				
<b><u>DOMESTIC TASKS</u></b>					
12	Manage their own money when they are out?				
13	Wash small items of clothing?				
14	Do their own housework?				
15	Do their own shopping?				
16	Do a full clothes wash?				
<b><u>LEISURE ACTIVITIES</u></b>					
17	Read newspapers or books?				
18	Use the telephone?				
19	Write letters?				
20	Go out socially?				
21	Manage their own garden?				
22	Drive a car?				

# SPEECH QUESTIONNAIRE

Please tick the most appropriate description of your relative's behaviour over the past 4 weeks, based on your experience with them

## *Speech*

1. Does he/she produce appropriate spoken responses to familiar phrases produced by you, such as 'Hello', 'Good morning' and 'Goodbye'.

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

2. Does he/she say any single words spontaneously (without any help from you)?

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

3. Does he/she say any single words in response to your questions?

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

4. Does he/she say 'yes' and 'no' spontaneously?

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

5. Does he/she say 'yes' and 'no' the right way round?

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

6. Does he/she say any common everyday phrases such as 'Hello', 'Goodbye', 'Please' and 'Thank you' spontaneously?

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

7. Does he/she say common everyday phrases appropriately?

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

8. Is his/her conversation appropriate?

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

9. Does he/she say phrases spontaneously?

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

**10. Does he/she say phrases in response to your questions?**

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

**11. Does he/she initiate spoken conversation with you?**

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

**12. Does he/she say sentences spontaneously?**

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

**13. Does he/she say sentences in response to your questions?**

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

**14. Is his/her speech slow or hesitant?**

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

*Understanding*

**1. Does he/she understand simple instructions given by you using gestures (signs with your hands such as pointing) if necessary?**

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

**2. Does he/she understand simple spoken instructions without use of gestures?**

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

**3. Does he/she understand general conversation with you about everyday topics?**

Never ☐ Rarely ☐ Sometimes ☐ Always/Often ☐

**4. Does he/she understand rapid conversation with more than one person?**

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐

**5. Does he/she understand complicated ideas and explanations?**

Always/Often ☐ Sometimes ☐ Rarely ☐ Never ☐



## RAYNERS HEDGE SCALES OF FUNCTIONAL INDEPENDENCE IV (COGNITIVE SCALE)

Below are some difficulties that people may experience with everyday tasks following a stroke. For each item, please rate how independent you think the person who has had the stroke has been over the past 4 weeks. Your ratings should be based on your observations of them. Please indicate your response by ticking the most appropriate box

		Independent and normal function	Independent but slow, clumsy or with aid	Supervision/ occasional minor help	Regular minor help/ occasional major help	Regular major help	Complete incapacity
1	Orientation (time, place and person)						
2	Memory function						
3	Communication						
4	Reading and writing						
5	Following instructions						
6	Judging angles, speeds, distances						
7	Finding way round						
8	Manage financial affairs (money, bills etc)						
9	Decision making						
10	Planning/problem solving						

# ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

## RELATIVE VERSION

### YOUR VIEWS ABOUT YOUR RELATIVE'S STROKE

Listed below are a number of symptoms that your relative may or may not have experienced in the past 4 weeks. Please indicate by circling *Yes* or *No*, whether they have experienced any of these symptoms in the past 4 weeks, and whether you believe that these symptoms are related to their stroke.

	My relative has experienced this symptom <i>in the past 4 weeks</i>			This symptom is <i>related to</i> their <i>stroke</i>	
	Yes	No		Yes	No
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No
Memory Difficulties	Yes	No	_____	Yes	No
Concentration Difficulties	Yes	No	_____	Yes	No
Speech Difficulties	Yes	No	_____	Yes	No
Visual Problems	Yes	No	_____	Yes	No
Paralysis on one side of their Body	Yes	No	_____	Yes	No
Changes in sensation	Yes	No	_____	Yes	No
Bladder/Bowel Problems	Yes	No	_____	Yes	No
Swallowing Difficulties	Yes	No	_____	Yes	No

We are interested in your own personal views of how you currently see your relative's stroke. We use the term 'stroke health condition' below to mean the symptoms, effects and the underlying medical condition/s associated with your relative's stroke. It is important that you answer these questions only in relation to your relative's stroke health condition not to any other condition that they have which is not related to their stroke.

Please indicate how much you agree or disagree with the following statements about their stroke health condition by ticking the appropriate box.

	<b>VIEWS ABOUT MY RELATIVE'S STROKE</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP1*	<b>My relative's stroke health condition will last a short time</b>					
IP2	<b>My relative's stroke health condition is likely to be permanent rather than temporary</b>					
IP3	<b>My relative's stroke health condition will last for a long time</b>					
IP4*	<b>This stroke health condition will pass quickly</b>					
IP5	<b>I expect my relative to have this stroke health condition for the rest of their life</b>					
IP6	<b>I believe that my relative's stroke health condition is serious for them</b>					
IP6	<b>I believe that my relative's stroke health condition is serious for me</b>					
IP7	<b>My relative's stroke health condition has major consequences on their life</b>					
IP7	<b>My relative's stroke health condition has major consequences on my life</b>					
IP8*	<b>My relative's stroke health condition does not have much effect on their life</b>					
IP8*	<b>My relative's stroke health condition does not have much effect on my life</b>					
IP9	<b>My relative's stroke health condition strongly affects the way others see them</b>					
IP9	<b>My relative's stroke health condition strongly affects the way others see me</b>					
IP10	<b>My relative's stroke health condition has serious financial consequences for them</b>					
IP10	<b>My relative's stroke health condition has serious financial consequences for me</b>					
IP11	<b>My relative's stroke health condition causes difficulties for those who are close to them</b>					
IP11	<b>My relative's stroke health condition causes difficulties for those who are close to me</b>					
IP12	<b>There is a lot which my relative can do to control their symptoms</b>					
IP12	<b>There is a lot which I can do to control my relative's symptoms</b>					
IP13	<b>What my relative does can determine whether their stroke health condition gets better or worse</b>					
IP13	<b>What I do can determine whether my relative's stroke health condition gets better or worse</b>					

	<b>VIEWS ABOUT MY RELATIVE'S STROKE</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP14	<b>The course of my relative's stroke health condition depends on me</b>					
IP15*	<b>Nothing my relative does will affect their stroke health condition</b>					
IP15*	<b>Nothing I do will affect my relative's stroke health condition</b>					
IP16	<b>My relative has the power to influence their stroke health condition</b>					
IP16	<b>I have the power to influence my relative's stroke health condition</b>					
IP17*	<b>My relative's actions will have no affect on the outcome of their stroke health condition</b>					
IP17*	<b>My actions will have no affect on the outcome of my relative's stroke health condition</b>					
IP18*	<b>My relative's stroke health condition will improve in time</b>					
IP19*	<b>There is very little that can be done to improve my relative's stroke health condition</b>					
IP20	<b>My relative's treatment will be effective in curing/managing their stroke health condition</b>					
IP21	<b>The negative effects of my relative's stroke health condition can be prevented (avoided) by their treatment</b>					
IP22	<b>My relative's treatment can control their stroke health condition</b>					
IP23*	<b>There is nothing which can help my relative's condition</b>					
IP24	<b>The symptoms of my relative's condition are puzzling to them</b>					
IP24	<b>The symptoms of my relative's condition are puzzling to me</b>					
IP25	<b>My relative's stroke health condition is a mystery to them</b>					
IP25	<b>My relative's stroke health condition is a mystery to me</b>					
IP26	<b>My relative doesn't understand their stroke health condition</b>					
IP26	<b>I don't understand my relative's stroke health condition</b>					
IP27	<b>My relative's stroke health condition doesn't make any sense to them</b>					
IP27	<b>My relative's stroke health condition doesn't make any sense to me</b>					
IP28*	<b>My relative has a clear picture or understanding of their condition</b>					
IP28*	<b>I have a clear picture or understanding of my relative's condition</b>					
IP29	<b>The symptoms of my relative's stroke health condition change a great deal from day to day</b>					
IP30	<b>My relative's symptoms come and go in cycles</b>					
IP31	<b>My relative's stroke health condition is very unpredictable</b>					
IP32	<b>My relative goes through cycles in which their stroke health condition gets better and worse</b>					

	<b>VIEWS ABOUT MY RELATIVE'S STROKE</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP33	<b>I get depressed when I think about my relative's stroke health condition</b>					
IP34	<b>When my relative thinks about their stroke health condition they get upset</b>					
IP34	<b>When I think about my relative's stroke health condition I get upset</b>					
IP35	<b>My relative's stroke health condition makes them feel angry</b>					
IP35	<b>My relative's stroke health condition makes me feel angry</b>					
IP36*	<b>My relative's stroke health condition does not worry them</b>					
IP36*	<b>My relative's stroke health condition does not worry me</b>					
IP37	<b>My relative having this stroke health condition makes them feel anxious</b>					
IP37	<b>My relative having this stroke health condition makes me feel anxious</b>					
IP38	<b>My relative's stroke health condition makes them feel afraid</b>					
IP38	<b>My relative's stroke health condition makes me feel afraid</b>					

Their own behaviour

Their personal attitude e.g. thinking about life negatively

Their problems or worries about their stroke

Their work

Their emotional state e.g. feeling down

Their physical ability

Ageing

Alcohol

Smoking

Accident or injury

Their personality

Visual memory

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR RELATIVE'S stroke health condition. You may see any of the items from the list above, or you may have a different idea of your own.

The most important causes for me are:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_



## CAUSES OF MY RELATIVE'S STROKE

We are interested in what you consider may have been the cause of your relative's stroke health condition. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused their stroke health condition rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for their stroke health condition. Please indicate how much you agree or disagree that they were causes for them by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in their family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in their past					
C7	Pollution in the environment					
C8	Their own behaviour					
C9	Their mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused their stroke					
C11	Overwork					
C12	Their emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	Their personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused **YOUR RELATIVE'S** stroke health condition. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## Brief COPE

We are interested in how people respond when they try to cope with their relative's stroke and its effects. There are many ways to try to deal with problems. These items ask what you have been doing to cope with your relative's stroke and its effects over the past 4 weeks. Obviously different people deal with things in different ways, but we are interested in how you have tried to deal with it.

Each item says something about a particular way of coping. We want to know to what extent or how frequently you've been doing what the items says over the past 4 weeks. Don't answer on the basis of whether it seems to be working or not - just whether or not you've been doing it over the past 4 weeks.

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully and make your answers as true **FOR YOU** as you can. Please answer every item. There are no right or wrong answers, so choose the most accurate answer for **YOU** – not what you think most people would say or do. Please indicate your response by ticking the most appropriate box.

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1	I've been turning to work or other activities to take my mind off things				
2	I've been concentrating my efforts on doing something about the situation I'm in				
3	I've been saying to myself "this isn't" real				
4	I've been using alcohol or other drugs to make myself feel better				
5	I've been getting emotional support from others				
6	I've been giving up trying to deal with it				
7	I've been taking action to try to make the situation better				
8	I've been refusing to believe that it has happened				
9	I've been saying things to let my unpleasant feelings escape				
10	I've been getting help and advice from other people				
11	I've been using alcohol or other drugs to help me get through it				
12	I've been trying to see it in a different light, to make it seem more positive				
13	I've been criticising myself				

		<b>I haven't been doing this at all</b>	<b>I've been doing this a little bit</b>	<b>I've been doing this a medium amount</b>	<b>I've been doing this a lot</b>
14	<b>I've been trying to come up with a strategy about what to do</b>				
15	<b>I've been getting comfort and understanding from someone</b>				
16	<b>I've been giving up the attempt to cope</b>				
17	<b>I've been looking for something good in what is happening</b>				
18	<b>I've been making jokes about it</b>				
19	<b>I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping</b>				
20	<b>I've been accepting the reality of the fact that it has happened</b>				
21	<b>I've been expressing my negative feelings</b>				
22	<b>I've been trying to find comfort in my religion or spiritual beliefs</b>				
23	<b>I've been trying to get advice or help from other people about what to do</b>				
24	<b>I've been learning to live with it</b>				
25	<b>I've been thinking hard about what steps to take</b>				
26	<b>I've been blaming myself for things that happened</b>				
27	<b>I've been praying or meditating</b>				
28	<b>I've been making fun of the situation</b>				